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FOREWORD

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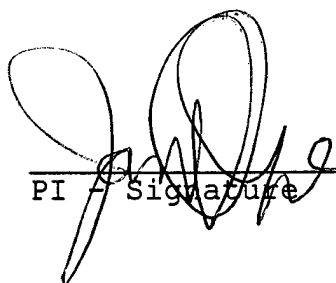
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INTRODUCTION

This project involves a prospective study of women who are at high risk for early onset breast cancer and their families in a time period spanning from prior to the offering of predictive testing to a year following their decision whether to obtain such testing. Predictive testing is now possible for mutations of both the BRCA1 and BRCA2 genes. Mutations of BRCA1 convey an 85% lifetime risk of breast cancer, as well as an unknown increase in the risk for ovarian cancer. Mutations of BRCA1 are thought to explain 15-25% of all inherited breast cancer and up to 90% of families with both breast and ovarian cancer. Mutations of BRCA2 carry a risk of breast cancer of 85% for women by age 80 and a risk of 15-20% for ovarian cancer by age 70. Mutations of BRCA2 also confer a risk of breast cancer in men of 6% by age 70. Mutations of BRCA2 are thought to explain 15-25% of all inherited breast cancer. As with BRCA1, current risk estimates for BRCA2 may change since these figures were derived from a skewed population of large, highly cancer-affected families and therefore may be overestimates.

Testing is already being offered to our research sample of high-risk women who have been participating in genetic linkage and mutation studies, and it has now also become commercially available. As many as 1 in 200-400 American women are carriers of mutations of these genes, and larger numbers can be expected to face the dilemma of whether to seek testing. Mutations of these genes are the first for which widespread testing for risk of late onset disease is appropriate, and the availability of the test raises some daunting and largely unprecedented issues. Women with positive family histories of breast cancer have expressed considerable interest in obtaining predictive testing. Yet little is known about the extent to which women who indicate they will utilize testing actually follow through, the anticipated benefits and drawbacks of knowledge of risk status influencing their choice, or about the psychological and social costs to these women and their families of having access to such information. Positive findings carry the threat of psychological and psychiatric morbidity for the women and family members, the disruption of family relationships, and the impairment of the women's surveillance and adherence behavior, but the degree of vulnerability and factors which identify the individuals and families at greatest vulnerability have not yet been determined. Yet, negative findings or not obtaining information concerning risk status may also have detrimental effects on the women and their families.

In the absence of a large body of directly relevant prior research, we are faced with an urgent need for basic descriptive data concerning women at high-risk for early onset breast cancer and their families; their psychosocial assets and liabilities, their attitudes and beliefs, their intention to seek predictive testing, and their preparedness for possible results. This information is needed immediately for planning for the implications of testing being made available on a such large scale basis. Yet, we also have a historical opportunity to utilize these data in a prospective study of stress, coping, and decision making processes in these women and their families with the advantage of initial data having been obtained just prior to predictive testing for BRCA1 becoming an option for the individual women.

The project involves a longitudinal study of a sample of at least 300 high-risk women who are among the first being offered the option of testing for BRCA1 and their family members. They receive baseline in-depth assessment by questionnaire and telephone interview, and initial assessments had been started at the point of receipt of funding from the DoD. Funding from the DoD Breast Cancer Initiative was sought to complete initial assessments and to follow the women over time with 4 reassessments: when testing for BRCA1 becomes available to the individual women, after receipt of any results, and 3 and 9 months after testing. Husbands of the high risk women are being assessed by questionnaire and they will be reassessed along with siblings of the women at the time of

the offering of testing to the individual women and again at 3 and 9 months after following testing. Our sample is well described medically and in terms of family history. The women and their families are being assessed with a set of psychosocial measures which are carefully chosen for their likelihood of immediate relevance to planning and the design of clinical protocols, but also for their use in understanding of basic individual and family stress and coping processes. Variables assessed include attitudes and beliefs; personality traits; social support and family functioning; psychological distress and psychiatric morbidity; and decisions and behavior relevant to their management of risk for cancer. These measures will also allow estimation of psychosocial costs associated with the option of testing and modeling of the intention whether to obtain testing and subsequent decision-making and behavior. The resulting longitudinal data will have a direct application in estimating the need for services, refining appropriate clinical protocols, and suggesting requisite training for personnel providing services.

The first overall objective of this study is to assess psychological distress, current and past psychiatric disorder and impairment in women at high-risk for breast and ovarian cancer who are anticipating the prospect of genetic testing. Establishing base rates of distress and impairment permits us to evaluate the mental health needs of these women anticipating testing, and it also serves as a first step toward evaluating the incremental distress incurred by risk notification. That is, levels of distress and morbidity following disclosure need to be evaluated in terms of what these levels were prior to disclosure. Apparently high rates of distress and disorder following testing might nevertheless represent a reduction from pre-existing levels. The second objective is to compare the two groups of women within our sample: One group who had been previously diagnosed with breast cancer, and one group who had not yet been affected. Initial differences between the two groups are important for the evaluation of the extent to which unaffected women subsequently become like affected women upon receipt of findings that they carry the altered gene. On the other hand, it might prove to be the case that heightened awareness of high risk status among unaffected women has already resulted in comparable levels of distress and disorder. A final objective is to evaluate the extent to which our self-report data are successful in identifying current and past psychiatric diagnoses. Self-report screening instruments are economical and readily administered, but tend to have the disadvantage of low specificity as a means of identifying psychiatric cases (Coyne, 1994). Furthermore, the prevalence of both distress and disorder in a given population may affect the performance of the cutpoint which has been established for screening measures. This, one study found that the high rates of elevated scores on a screening instrument, but low levels of depression among adolescents rendered the established cutpoint for the screening instrument useless in detecting depression (Roberts, Lewinsohn, & Seeley, 1991). The inclusion of both self-report measures and diagnoses based on semi-structured interview allows us to examine the performance of the self-report measures in terms of their possible use as the first stage of two-stage strategies for identifying psychiatric morbidity. Even if their specificity proved to be as modest as anticipated, low scores might still prove valuable in screening out women who would be unlikely to be found to have psychiatric morbidity in a diagnostic interview.

BODY

The project involves an in-depth assessment and tracking of four interrelated groups: (1) at least 300 proband women (presently 480) who have a risk for early onset breast cancer based on two or more affected relatives and who will be among the first persons to have access to predictive testing for BRCA1 mutation; (2) the spouses of the approximately 230 women who are married; (3) a stratified random sampling of 120 of the women's unaffected sisters (those who have not been diagnosed with breast cancer) and (4) 80

brothers. Key variables include the women and family members' stress and social support processes, including cancer-related stress and support; psychological distress and psychiatric morbidity; marital and family functioning; psychological characteristics presumed to affect the women's information-processing, decision-making, and subsequent adjustment; and the at-risk women's intentions to seek predictive testing and anticipated outcomes and plans for use of the information; relevant attitudes, beliefs, and expectations; and current surveillance and adherence behaviors. Assessment of the proband women is by self-report questionnaires and telephone interviews. Subsequent reassessments of the proband women's current cancer-related stress and support and beliefs, attitudes and intentions, distress, and psychiatric morbidity will also be by telephone interview and questionnaire. Assessments of husbands and siblings will be by self-report questionnaires within a month of receipt of funding. The at-risk women, spouses and siblings will then be reassessed as the option of predictive testing is made available to the individual women. A second reassessment will occur after testing has occurred and results are available, or when results would have been available had the proband woman not declined testing. A third reassessment will occur 4-8 weeks later after results are provided, and follow up assessments will occur at 6 and 12 months.

PROCEDURE AND ACCOMPLISHMENTS TO DATE

Summary

The first year was marked by the meeting of key objectives and successful confrontation with a variety of challenges and opportunities. Expansion of the Hereditary Breast and Ovarian Cancer Registry from which subjects are drawn allowed recruitment of a larger sample for baseline assessment. This was fortuitous because preliminary testing of blood samples from women already affected by breast and ovarian cancer in high risk families has now revealed that BRCA1 and BRCA2 account for less of the ostensibly hereditary breast cancer than previously predicted. At the present time, women from families that do not have an affected woman with a BRCA1 or BRCA2 mutation may not be offered testing. The implications of this are that many of the women in our sample will not progress to the stage of actually confronting the testing dilemma. Our substantially augmented sample allows us to nonetheless have a more than adequate size and statistical power for women who do progress to a choice about testing. The first year was also marked by delays in the offering of testing to individual women for a variety of technical and practical reasons spelled out below. We had anticipated this and had previously designed an interim assessment to be administered if one year passed after baseline assessment without a woman being offered testing. This interim assessment also served to reduce the burden of the baseline assessment by redistributing some of our trait measures to a second testing and it also involved the re-administration of measures of distress and other state variables likely to fluctuate over such a time period. As planned, women who progressed to having a choice about testing received these measures in their pre-counseling assessment. We also took advantage of a change in the of the Hereditary Breast and Ovarian Cancer Registry. Persons, both male and female, who have gotten results of genetic testing elsewhere are now being entered into the registry for the purposes of long term follow up. We have included them in our tracking sample. For some purposes they will be separated for data analysis, but for other purposes, they can be combined. This addition will very likely make our sample the largest data base concerning persons who have received genetic testing for risk of breast cancer.

Data cleaning, reduction, and entry are proceeding well. One of our objectives has been to produce as quickly as possible an assessment of baseline distress and psychiatric morbidity

among women anticipating genetic testing. This has been done, and the results are presented below. As we noted, these women are freer of problems than anticipated and we are now conducting analyses to understand this in terms of their social resources and family experience with cancer.

Methods

Women and their families participating in this study were drawn from the Hereditary Breast and Ovarian Cancer Registry originally started at the University of Michigan, but now housed at the University of Pennsylvania. To be included in the registry, unaffected women had to have at least two cases of either breast or ovarian cancer in their family, and affected women had to have at least one family member who had been affected. An alternative inclusion criterion was for women to have had ovarian cancer after prophylactic oophorectomy. A periodic informational letter to women enrolled in the registry made reference to the possibility of an impending longitudinal study of them and family members. To recruit subjects for the this psychosocial component of the University of Michigan/ University of Pennsylvania study, a cover letter, consent form, and questionnaire were sent to eligible enrollees in the registry. When the baseline questionnaire and consent form were returned, subjects were contacted by telephone in order to answer any questions and schedule the telephone interview. If we received neither a questionnaire or a mailback refusal form, we called subjects, explained the study, and offered to send another packet if necessary. At the point of actual receipt of funding, some of the women had already participated in the initial assessment and had been alerted to the possibility of their being asked to continue in a longitudinal study and to enlist family members. Women continuing to participate in the study will be again asked to solicit the involvement of spouses. Given the sensitive nature of risk information, concerns about confidentiality dictated that we utilize the women rather than contact the family members directly. We discussed the rationale with the women for their family members' involvement, underscored the voluntary nature of their choice whether to facilitate their family members' participation in the study, and if they so chose, provided them with strategies for contacting and enlisting them. Such preparation and training of the proband women had already been successfully used in obtaining initial and follow up biomedical and family history data from these families. When we were notified by women that family members had agreed to participate, we called them, explained the study, and sent a packet with a questionnaire and consent form.

The next scheduled assessment of the women is the Pre-Results and a number of the women and their siblings have either completed this assessment or recently received it.

Our ability to track these women and their families through the course of their being offered testing is dependent upon their actually being given this opportunity. A number of factors have affected the offering of testing in general and to specific individuals. Actual testing is now proceeding in our sample, but after considerable delay and only to certain individuals. Technology for genetic testing has been available for some time, but mutation analysis remains challenging. Both BRCA1 and BRCA2 are very large genes and mutations are scattered throughout the genes. Analyses of either of the entire genes would be labor intensive and expensive. Available laboratory techniques do not detect mutations on non-coded regions of the genes, but these may account for as many as 5-10% of mutations. Therefore, at the present time, the accuracy and informativeness of testing is hinged upon whether there is a known mutation of BRCA1 or BRCA2 identified in an individual in the family affected with either breast or ovarian cancer. If such a known mutation exists, then the detection of that mutation in another member of that family is highly accurate and informative. If no such mutation has been identified in a particular

family, then the only informative result for individual family members is when a mutation of BRCA1 or BRCA2 is identified. In the absence of mutation having been found in a family, a negative testing finding for a given individual is not informative. If a mutation is not identified for this individual, it does not mean that the cancer is not associated with a cancer susceptibility gene, only that no such mutation can be identified at this time. The net result of all of these considerations is not every individual is appropriate for testing. For the University of Pennsylvania Hereditary Breast and Ovarian Cancer Registry, the decision was made to analyze already collected blood samples from affected women. If an affected woman was found to have a mutation, testing was offered to her family. As in other hereditary breast cancer registries, it is being found that many ostensibly high risk families do not carry a known mutation of BRCA1 or BRCA2. This is stimulating a search for other genes associated with risk of breast cancer, but it also means that for now many women in the sample will not receive testing. Some have already been sent a letter explaining the predicament of their families with respect to testing. These women will continue to be studied. Essentially they had met criteria for inclusion in the registry, and based on this, they were led to believe that genetic testing would be an option. They are not being told that they are not members of a hereditary breast and ovarian cancer family, only that the families are not characterized by a known mutation of BRCA1 or BRCA2. This outcome is worthy of investigation and may have attendant psychological distress and other untoward consequences associated with it. Fortunately, we have baseline assessments of these women.

Women in the Hereditary Breast and Ovarian Cancer Registry are scattered across the country. In order to receive results, women who are not in close proximity to the University of Pennsylvania, University of Michigan, or other select sites must identify a physician and through that physician, provide a clinical consent. Only then will results be released. The shortage of such physicians and some difficulties in their understanding of the consent process has led to some delays, but release of test results is now proceeding. Concerted efforts are being made nationally to increase the availability of individuals qualified for counseling, disclosure of results, and follow up. We are coordinating our assessments with information from the University of Pennsylvania and collecting data as women proceed through the process of getting the opportunity to obtain test results.

Measures

Our selection of measures conforms to our original proposal. Copies of our batteries of instruments are included as an appendix. Table 1 lists the major measures.

Table 1: Initial Data CollectionProband Women

<u>Questionnaire</u>	<u>Interview</u>	<u>Interim Assessment</u>
Demographics	Contextual Rating of	HSCL-25, MOS-36
Health Locus of Control	Cancer Threat:	Cancer Worries
Risk Perception	Affected Relatives	FAD, Short-Form DAS
Intention to Seek Testing	Relationship to	Quality of Social Support
Knowledge, Beliefs and	Proband	Life Cycle Issues
Attitudes	Outcome	Receipt of Individual,
Reasons for Seeking Testing	Involvement of	Group, & Family,
Anticipated Reactions	Proband In Care	Counseling & Education
Cancer Worries	Effects on Proband's	COPE
Stressful Life Events	Life	Relationship-Focused
Optimism (LOT)	SCID Depression , Anxiety,	Coping
Miller Behavioral Styles	& Substance Use Modules	CBCL
Scale (MBSS)	Cancer-Specific Support	Evaluation of Preventive
Hopkins-25, MOS-36,	Processes	Options
AUDIT		
Present and Future Self-Concept		
Dyadic Adjustment (DAS)		
General Family Functioning (FAD)		
Social Support & Cancer-Related Support Processes		

Husbands Questionnaire

Demographics	COPE	Stressful Life Events
Health Locus of Control	Knowledge, Beliefs and	CBCL
Risk Perception	Attitudes Anticipated	LOT, MBSS, Hopkins-25,
Worries About Wife's	Reactions	MOS-36
Risk of Cancer	Social Support & Cancer-	AUDIT
Preference for Wife's	Related	DAS, FAD
Testing	Support Processes	
Relationship-Focused		
Coping		

Sample

Our sample currently consists of 480 women who have completed baseline assessments. Of these, 472 completed the telephone interviews. To date, 301 interim assessments have been collected. Data from husbands are collected at the point of the women's interim assessment, the first husband data are collected, and at this time, data have been collected from 177 husbands. Pre-Results data have been collected from 10 Probands and 4 siblings. In addition, follow up data have been collected from 15 men and women in the long term follow up subsample. Table 2 presents basic demographic data on the proband women. As can be seen, they are similar to other samples of persons seeking genetic services in that they are relatively well educated and high income.

Table 2
Basic Demographic Data

	<u>ALL WOMEN</u>	<u>UNAFFECTED WOMEN</u>	<u>AFFECTED WOMEN</u>
Age	52.7(12.2)	51.0(13.3)	54.2(11.0)
Religion Christian	77.7%	81.6%	74.1%
Marital Status Married/With Partner	83.1%	83.1%	82.9%
Number of Children	2.31(1.38)	2.26(1.51)	2.36(1.27)
Education At Least Some College	75.8%	71.4%	80%
Employed Outside Home	54.8%	55.8%	53.8%
Income	\$56,800	\$4,500	\$59,100

Study of Baseline Distress and Psychiatric Morbidity

As we noted, one of objectives for the first year was to finish collecting and to analyze baseline data concerning psychological distress and psychiatric morbidity. The Hopkins Symptom Checklist served as the measure of distress and a telephone interview using modules of the SCID served as the measure of current and lifetime psychiatric morbidity. These data were analyzed in conjunction with baseline concerning intention to get test results and cancer worries.

Psychological Distress. The 25 item version of the Hopkins Symptom Checklist (HSCL-25) was used to assess psychological distress. Heshbacher, Downing, and Stephansky (1978), found this version of the questionnaire reliable and highly correlated with the standard 58-item version (Derogatis et al., 1974). The HSCL-25 has a better balance of sensitivity and specificity than a number of other screening instruments such as the CES-D (Heshbacher et al. 1978; Hough et al. 1982). There is extensive data using this scale with healthy, physically ill, and psychiatric samples (Cohen, Coyne, & Duvall, 1993; Coyne & Smith, 1991; Coyne & Sonnega, 1995, Pepper & Coyne, 1996).

Current Depression, Anxiety, and Alcohol Use Disorders and History of Depression. Like other self-report screening instruments, our measures of psychological distress and alcohol

use have good sensitivity, but poorer specificity and they do not provide for diagnoses. A 2-stage screening in strategy is therefore appropriate (Dohrenwend & Shrout 1981; Newman, Shrout, Bland 1990). Women with elevated scores on measures of psychological distress and alcohol use and a subsample of those scoring below the cut points will be administered corresponding alcohol use and/or depression and anxiety and sections of the Structured Clinical Interview for DSM-IV (SCID-IP; First et al 1994).

The SCID utilizes trained mental health professionals and yields DSM-IV diagnoses. In addition to diagnoses, the SCID includes assessment of the severity of major depression according to DSM-IV criteria and assessment of past history of depression. The DIS utilizes lay interviewers, and one key difference between the two instruments is that the SCID utilizes the clinical judgment of the interviewer for decisions about explaining or rephrasing questions and accepting or probing respondents' answers. In contrast, the DIS is more like an interviewer-administered questionnaire with considerable constraint on what the interviewer can ask or infer (Coyne, 1994). Although the DIS has been used in the large scale ECA Study (Regier, Myers & Kramer 1984), there is some evidence of substantial discrepancy between the diagnoses made by lay interviewers using the DIS and standardized diagnoses made by psychiatrists (Anthony et al 1985). Moreover, discordance may be more frequent with nonpsychiatric populations when the depression being diagnosed is mild so that criteria are barely met by alternative rules, and this proves particularly important when correlates are examined rather than simple rates of detection (for a fuller comparison of the SCID-IP and DIS, see Coyne 1994). Discordance is similarly likely to arise when judgments must be made whether to consider heightened distress as an adjustment reaction, and such decisions are likely to be routine in assessing the proband women.

The SCID-IP is designed for use in a modular fashion so that an investigator can select, for a particular study, only those diagnostic modules that are relevant for a particular patient sample. For our purposes, the SCID-IP is modularized to assess history of depression and current mood disorders, alcohol use disorders, panic disorders, and generalized anxiety, and adjustment disorders. This decision is based on our own experience assessing psychiatric disorder in primary care, but also the NYSPI experience assessing homosexual men seeking testing for HIV antibody (Williams et al 1991). They initially included psychotic screening questions, the other anxiety disorders, and somatoform disorders but these areas of psychopathology were virtually never detected, so they dropped these sections to decrease interviewing time.

Questions can be raised about the conduct of diagnostic interviews by telephone. However, previous studies have shown the concordance of phone-administered diagnostic interviews with face-to-face interviews (Kendall et al 1992; Wells et al 1988; Potts et al 1990; Baer et al 1993), and as with other major research centers, we have been having satisfactory experiences with telephone interviewing.

Cancer worries. This measure was administered to the unaffected group only. The women were asked how often they worry about developing breast cancer and also the extent to which their worries interfered with their everyday lives. These measures had been validated in studies conducted by Caryn Lerman and her colleagues e.g. Lerman et al. 1994; Lerman & Croyle, in press; Struewing et al., in press).

Table 3 presents data concerning the intention to receive testing when it is offered. As can be seen, the majority of women express interest in obtaining results, but it remains to be seen the extent to which this expression of interest is reflected in the women actually choosing to receive their results when the opportunity is presented to them. This will undoubtedly prove to be an overestimate of the actual uptake of testing.

Table 3
Intention To Be Tested For Brcal (%)

	<u>ALL WOMEN</u>	<u>UNAFFECTED WOMEN</u>	<u>AFFECTED WOMEN</u>
Definitely Will Immediately	64.2	55.2	75.0***
Definitely, Not Sure Immediately	10.2	15.5	4.2
Probably Will Immediately	9.4	9.7	9.2
Probably Will Not Immediately	4.1	9.0	4.2
Undecided	7.2	9.0	5.0
Probably Will Not	1.9	1.4	2.5
Definitely Will Not	0.4	0.7	0

***p<.001

Table 4 (next page) provides data concerning the women's reasons for obtaining test results. While their motivation to reduce uncertainty was expected, it is noteworthy that the next strongest reason for the full sample is to find out about their children. This result is consistent with our anticipation of the salience of such family issues in the reasons for getting testing.

Table 4
Reasons For Seeking Testing

	<u>ALL WOMEN</u>	<u>UNAFFECTED WOMEN</u>	<u>AFFECTED WOMEN</u>
To Plan for Future	46.4	62.7	30.7***
To Reduce Uncertainty	64.6	79.4	48.2***
To Be More Careful About BSE	34.6	46.0	21.9
To Decide About Prophylactic Surgery	47.1	55.6	32.5***
To Decide About Family Planning	5.8	11.9	2.6
To Assess Risk To Children	61.7	51.6	72.8**
Family Urges Testing	17.4	15.1	13.2
	*p<.05	**p<.01	***p<.001

Table 5 provides data concerning these women's perceived risk of breast cancer. These women's estimates of their risk is not inconsistent with being a female member of a high risk family.

Table 5
Perceived Likelihood Of Breast Cancer

	<u>ALL WOMEN</u>	<u>UNAFFECTED WOMEN</u>	<u>AFFECTED WOMEN</u>
In the Near Future	35.2%	44.7%***	22.3%
In Lifetime	47.8%	60.3%***	31.9%

Table 6 presents the results obtained with the Hopkins Symptom Checklist. Interpretation of these results is assisted by making a comparison with our HSL-25 data obtained with other samples, presented in Table 7. Our sample, both affected and unaffected, is remarkable free of distress. This disconfirms expectations that at risk women seeking testing are a highly distressed group.

Table 6
Psychological Distress

	<u>All Women</u>	<u>Unaffected Women</u>	<u>Affected Women</u>
Hopkins 25	37.5 (9.2)	37.4 (9.2)	37.7 (9.2)
% Above Cutoff	21%	21%	22.8%

Table 7
Psychological Distress In Other Samples

Cohen, Coyne, Duvall (1993):

Adoptive Nonclinical Mothers	34.52 (7.09)
Biological Nonclinical Mothers	36.25 (8.9)
Adoptive Clinical Mothers	43.64 (12.3)
Biological Clinical Mothers	41.30 (12.1)

Coyne & Smith (1991)

Wives of Post-MI Patients	41.8 (10.2)	32%
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Coyne & Sonnega (1995)

Wives of CHF Patients	47.1 (12.8)	49%
Female CHF Patients	46.6 (14.1)	62%

Pepper & Coyne (1996)

Depressed Female Outpatients	65.0 (11.30)
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Table 8 presents the results obtained in the assessment of psychiatric morbidity using the telephone-administered SCID modules. Consistent with the data concerning psychological distress, this is a remarkably intact group of women, given their high risk status. The lifetime rates of depression are well within normal limits, but their rates of current disorder are even lower than what is found in representative samples of community residing women. Thus, the anticipation by some that these women would have a high prevalence of depression and anxiety disorders was clearly not confirmed.

Table 8
Psychiatric Morbidity (%)

	<u>ALL WOMEN</u>	<u>UNAFFECTED WOMEN</u>	<u>AFFECTED WOMEN</u>
Current Major Depression	1.1	0.4	1.9
Lifetime Major Depression	18.4	15.8	21.5
Current Major Depression (GMC)	0.2	0.5	0
Lifetime Major Depression (GMC)	2.1	1.2	3.2
General Anxiety Disorder	0.6	0.8	0.5
Mixed Anxiety/Depression	0.6	1.2	0

Finally, Table 9 presents the data derived from standard measures of breast cancer worries. Understandably, the women have a moderate degree of such worries, but what is noteworthy is that the follow up question concerning impairment indicates that such worries do not substantially interfere with their lives.

Table 9
Breast Cancer Worries Among Unaffected High Risk Women

How often do you worry about developing breast cancer (1= Not at All, 5= All the Time)?	2.87
To what extent do any worries about breast cancer interfere with your life (1= Not at All, 5= All the Time)?	1.63

DISCUSSION

The women in our sample were remarkably free of psychological distress and psychiatric morbidity. Despite their increased risk for breast and ovarian cancer as well as their repeated exposure to breast cancer either in themselves or their relatives, they compared well with women drawn from other samples. Our findings have a number of implications. Most importantly, it appears that when the women approach the process of counseling, education, and decision making about testing, they will not be impaired by their pre-existing psychological state. That is not to say that the actual experience of counseling, having to make a decision about testing, or the receipt of positive results will not engender distress. However, the assumption that these women will approach the process of genetic testing with distress and psychiatric morbidity was not substantiated by our findings. Rather, the results suggest that any substantial elevations of distress and psychiatric morbidity following the counseling process are best attributed to that process and not to the preexisting state of the women. It follows that efforts to manage psychological distress and the education and consent process should focus on acute needs, rather than be based on the assumption of chronic psychological problems.

The findings reported in this study have a number of implications that go beyond the question of determining the psychological state of women seeking predictive testing for risk of breast cancer. We have demonstrated that long-term survivors of cancer can be relatively free of psychological distress and psychiatric morbidity. Even though over half our sample were survivors of breast cancer and had a greater lifetime incidence of depression than the unaffected women, these women were well within the expected prevalence for a representative sample of community residing women. The low levels of distress and morbidity reported in this study suggest that previous findings of elevated distress may be confined to early adjustment to a diagnosis of cancer, or to the advanced stages of the disease. Our findings add to accumulating evidence that cancer does not necessarily result in psychiatric morbidity. Moreover, the discrepancy between the levels of distress in our sample and the levels of psychiatric morbidity, further heightens the importance of not inferring psychiatric disorder from elevated distress.

We set out to examine the psychological vulnerability of women anticipating genetic testing. What we have ended up demonstrating is the resilience of these women. We believe that attention can be profitably turned to better understanding why these women defy the not unreasonable assumption that they are a distressed, depressed, and anxious group. The experience of living with familial risk of cancer may well have had a resiliency-building effect that more than cancels any vulnerability associated with it. The particular aspects of this experience that cultivate resiliency and vulnerability need to be specified. As others have noted, adversity can produce resiliency as well as vulnerability, and women anticipating testing provide an excellent opportunity to study this (e.g., Schaeffer & Moos, 1992).

The suggestion from the Huntington disease studies is that persons who are at risk, and who have received positive results do not experience long-term negative psychological consequences. Despite these findings, there has been some tendency to dismiss this as denial. We take issue with this. Our findings of a lack of morbidity were based on validated measures of self-reported distress and carefully constructed interviews. We are concerned about pathologizing what appears to be good adjustment. The claim that this only represents psychological defensiveness or maladjustment needs to be substantiated with measures of these presumed processes and not simply established on the basis that these people are low on disorder and morbidity. We favor of a more charitable explanation of the low levels of distress and impairment in high risk women, and propose that for both affected and unaffected women, genetic testing is ostensibly an acute stressor, but it has the

prospect of resolving a longer term stress process by reducing uncertainty. Women who come from families where there is a high incidence of breast or ovarian cancer are likely to have preconceptions of their risk for breast cancer as well as of their options for dealing with it. Though we might presuppose that the anticipation of testing may be stressful, for some women it is an opportunity to confirm what they believe they already know and to organize their lives accordingly. For others there is the hope that contrary to their existing perception of risk for cancer, they will be found not to have the gene.

CONCLUSION

In the first year, our project made substantial progress in its implementation, confronting of a methodological and logistical challenges and its timely production of empirical results concerning the baseline adjustment of these high risk women anticipating the opportunity to receive genetic testing for risk of breast and ovarian cancer. The excellent mental health of these women is reassuring and shifts the focus of our research from efforts to predict baseline vulnerability to efforts to understand their resiliency in the face of their risk for breast cancer. As a byproduct of this effort, we were able to produce data from our affected women which are optimistic concerning the mental health of longer term cancer survivors.

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APPENDICES

Included with this report are copies of all of the questionnaires used to date:

- Women's Health Study Questionnaire (Baseline Questionnaire)
- Telephone Questionnaire
- SCID Questionnaire
- Interim Questionnaires (Affected and Unaffected Versions)
- Spouse/Partner Questionnaires (Affected and Unaffected Versions)
- Proband Pre-Results Questionnaires (Affected and Unaffected Versions)
- Siblings Pre-Results Questionnaires
- Proband Post-Results Questionnaire

☐ ☐ ☐ ☐ - ☐



University of Michigan
Medical Center

WOMEN'S HEALTH STUDY QUESTIONNAIRE

Phone Number _____

Best time to reach you:

- Weekdays ☐
- Weekday evenings ☐
- Weekend days ☐
- Weekend evenings ☐
- Anytime ☐

Other: _____

Is there an alternative phone number where we may reach you?

110. What is your household's total income (all sources)?

<input type="checkbox"/> Less than \$10,000	<input type="checkbox"/> \$10,000 to \$19,999	<input type="checkbox"/> \$20,000 to \$29,999
<input type="checkbox"/> \$30,000 to \$39,999	<input type="checkbox"/> \$40,000 to \$49,999	<input type="checkbox"/> \$50,000 to \$59,999
<input type="checkbox"/> \$60,000 to \$69,999	<input type="checkbox"/> Greater than \$69,999	

- A11. How many people (adults and children) does this income support? _____
- B1. When were you first diagnosed with breast cancer? Month _____ Year _____
- B2. Have your lymph nodes been affected?
 Yes ☐ No ☐ Do Not Know ☐
- B3. Do you currently consider yourself in remission?
 Yes ☐ No ☐ Do Not Know ☐
- B4. What treatment(s) have you received for breast cancer?
 Chemotherapy Yes ☐ No ☐
 Radiation Yes ☐ No ☐
 Surgery Yes ☐ No ☐
- B5. Have you ever been diagnosed with ovarian cancer? Yes ☐ No ☐
 If yes, when? Month _____ Year _____
- B6. Have you ever had any of the following surgical procedures? (Please check all that apply).
- B6a. _____ Lumpectomy (Removal of lump from breast)
 If yes, when? Month _____ Year _____
- B6b. _____ Oophorectomy (Removal of ovaries)
 If yes, when? Month _____ Year _____
- B6c. _____ Unilateral mastectomy (Removal of one breast)
 If yes, when? Month _____ Year _____
- B6d. _____ Hysterectomy (Removal of uterus)
 If yes, when? Month _____ Year _____
- B6e. _____ Bilateral mastectomy (Removal of both breasts)
 If yes, when? Month _____ Year _____
- B7. Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to the average woman? (Please circle one)
 Much Less Likely Much More Likely
 1 2 3 4 5
- B8. Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to other women in your family? (Please circle one)
 Much Less Likely Much More Likely
 1 2 3 4 5
- B9. Overall, what do you believe your risk is of developing breast cancer again in the near future?
 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
- B10. Overall, what do you believe your risk is of developing breast cancer again at some point in your lifetime?
 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
- B11. Overall, what do you believe your risk is of developing a metasis (cancer spreading to another site) in the near future?
 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

- B12. Overall, what do you believe your risk is of developing a metasis **at some point in your lifetime?**
 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
- B13. Overall, what do you believe your risk is of developing cancer **unrelated** to your breast cancer **in the near future?**
 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
- B14. Overall, what do you believe your risk is of developing cancer **unrelated** to your breast cancer **at some point in your lifetime?**
 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
- B15. A medical test may soon be available that allows some women to learn their genetic risk for developing a form of breast and ovarian cancer that runs in families. Even though you have been diagnosed with breast cancer, would you consider taking the genetic test to learn if your cancer is the type that runs in families? (**Please check one response**).
- _____ I will **definitely** take the test immediately when it becomes available.
- _____ I will **definitely** take the test, but I am not sure if immediately.
- _____ I will **probably** take the test immediately when it becomes available.
- _____ I will **probably** take the test, but not immediately.
- _____ I am **undecided** whether I will take the test.
- _____ I will **probably not** take the test.
- _____ I will **definitely not** take the test.
- B16. If you think you will probably or definitely take the test, what are your reasons for doing so? (**Please check all that apply; some may not apply to you**).
- _____ To plan for the future.
- _____ To reduce the uncertainty.
- _____ To know I have to be more careful about doing self examinations and getting regular checkups.
- _____ To make decisions about whether to get preventive surgery.
- _____ To make decisions about family planning.
- _____ To find out the risk that may be transmitted to my children.
- _____ Family members want me to get testing.
- _____ Other (describe) _____
- B17. If you **do not** think you will probably or definitely take the test, what are your reasons for **not** doing so? (**Please check all that apply; some may not apply to you**).
- _____ I am happier not knowing.
- _____ It would be too upsetting to learn that I am at high risk for breast cancer.
- _____ I believe I already know what my risk for breast cancer is.
- _____ There would not be much I could do if I found out I was at high risk for breast cancer.
- _____ I do not feel able emotionally to deal with testing.
- _____ Family members do not want me to get testing.
- _____ Risk to my insurance coverage.

For the next questions we are interested in how people close to you respond to you when you are in need of support or reassurance. In answering the questions in the **first column**, please keep in mind a female family member who may be at risk for breast cancer **with whom you are closest**. Answer the questions in the **second column** keeping in mind **your spouse or intimate partner**. *If you do not have a spouse or intimate partner, please leave the second column blank.* For the **third column**, please keep in mind **another family member or friend to whom you are closest**.

	Female Family Member at Risk for Breast Cancer	Spouse/Partner	Another Family Member/ Friend
C1. Was physically present when you needed them.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C2. Told you what he/she did in a similar situation.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C3. Did activities to help you get your mind off things.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C4. Told you that the things you talk about are private--just between the two of you.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C5. Suggested some action you should take.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C6. Comforted you by showing you physical affection.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C7. Listened to you talk about your private feelings.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C8. Agreed that what you want to do is right.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C9. Told you how he/she felt in a similar situation.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C10. Let you know that he/she will always be around if you need assistance.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C11. Gave you feedback on how you were doing without saying it was good or bad.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C12. Pitched in and helped you do things that needed to get done.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C13. Intruded into your personal feelings and concerns.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C14. Gave you unsolicited advice.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C15. Attempted to make unwanted contact.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C16. Discouraged you from discussing your feelings and concerns.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C17. Minimized your worries or concerns.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C18. Rejected you for displaying emotional upset.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C19. Insisted that you remain upbeat and optimistic.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C20. Let you down when you were counting on him/her.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No

C21. Is there anyone in your life with whom you can share your most private feelings without holding back?

☐ Yes

☐ No

C21a. **If you are married or living with a partner**, can you share your most private feelings with this partner without holding back?

☐ Yes

☐ No

D1. Have any of the events listed happened to you in the past six months? **(Check All That Apply)**

- | | |
|---|--|
| a. <input type="checkbox"/> You retired or were fired or laid off from work. | g. <input type="checkbox"/> A close family member was seriously ill or injured. |
| b. <input type="checkbox"/> You were unemployed and looking for work. | h. <input type="checkbox"/> You had a marital separation or divorce. |
| c. <input type="checkbox"/> Your spouse retired or was fired or laid off from work. | i. <input type="checkbox"/> You had serious troubles with relatives or close friends. |
| d. <input type="checkbox"/> Your spouse was unemployed and looking for work. | j. <input type="checkbox"/> Your spouse had troubles difficulties with relatives or close friends. |
| e. <input type="checkbox"/> You had problems with the police or court. | k. <input type="checkbox"/> A close family member died. |
| f. <input type="checkbox"/> You got into serious financial difficulties. | l. <input type="checkbox"/> A close friend or relative died. |
| | m. <input type="checkbox"/> You were seriously ill or injured. |

For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. Try to be as accurate and as honest as you can, and try not to let your answer to one question influence your answers to other questions. There are no right or wrong answers. We are only interested in your opinions.

		Strongly Disagree		Neutral		Strongly Agree
E1.	In uncertain times, I usually expect the best.	1	2	3	4	5
E2.	It's easy for me to relax.	1	2	3	4	5
E3.	If something can go wrong for me, it will.	1	2	3	4	5
E4.	I always look on the bright side of things.	1	2	3	4	5
E5.	I'm always optimistic about my future.	1	2	3	4	5
E6.	I enjoy my friends a lot.	1	2	3	4	5
E7.	It's important for me to keep busy.	1	2	3	4	5
E8.	I hardly ever expect things to go my way.	1	2	3	4	5
E9.	Things never work out the way I want them to	1	2	3	4	5
E10.	I don't get upset too easily.	1	2	3	4	5
E11.	I'm a believer in the idea that "every cloud has a silver lining".	1	2	3	4	5
E12.	I rarely count on good things happening to me.	1	2	3	4	5

Below is a list of words which people might use to describe themselves. You are asked to rate them **twice**. First, please indicate for each word **how well it describes you** and second, **how much it matters to you** using the following scale.

1	2	3	4	5
Extremely	Very much	Somewhat	Not very well	Not at all

		<u>DESCRIBES ME</u>					<u>MATTERS TO ME</u>				
		1	2	3	4	5	1	2	3	4	5
F1.	Involved in family	1	2	3	4	5	1	2	3	4	5
F2.	Aware of being a woman	1	2	3	4	5	1	2	3	4	5
F3.	Involved in paid work	1	2	3	4	5	1	2	3	4	5
F4.	Being a mother	1	2	3	4	5	1	2	3	4	5
F5.	Involved in organization/ volunteer work	1	2	3	4	5	1	2	3	4	5
F6.	Being a grandmother	1	2	3	4	5	1	2	3	4	5
F7.	Physically attractive	1	2	3	4	5	1	2	3	4	5
F8.	Being a wife	1	2	3	4	5	1	2	3	4	5
F9.	Healthy	1	2	3	4	5	1	2	3	4	5
F10.	Being a daughter	1	2	3	4	5	1	2	3	4	5
F11.	Intelligent	1	2	3	4	5	1	2	3	4	5
F12.	Able to cope	1	2	3	4	5	1	2	3	4	5
F13.	Spiritual or religious	1	2	3	4	5	1	2	3	4	5
F14.	Outgoing	1	2	3	4	5	1	2	3	4	5
F15.	Independent	1	2	3	4	5	1	2	3	4	5
F16.	Realistic	1	2	3	4	5	1	2	3	4	5
F17.	Active	1	2	3	4	5	1	2	3	4	5
F18.	Loved	1	2	3	4	5	1	2	3	4	5
F19.	Caring	1	2	3	4	5	1	2	3	4	5
F20.	Depressed	1	2	3	4	5	1	2	3	4	5

In the next table, we would like you to first rate how well you think each word will describe you *in the future*, and then, indicate how important it is for you to see yourself this way *in the future*.

1	2	3	4	5
Extremely	Very much	Somewhat	Not very well	Not at all

		<u>WILL DESCRIBE YOU</u>					<u>IMPORTANT FOR YOU TO SEE YOURSELF THIS WAY IN FUTURE</u>				
		1	2	3	4	5	1	2	3	4	5
G1.	Involved in family	1	2	3	4	5	1	2	3	4	5
G2.	Aware of being a woman	1	2	3	4	5	1	2	3	4	5
G3.	Involved in paid work	1	2	3	4	5	1	2	3	4	5
G4.	Being a mother	1	2	3	4	5	1	2	3	4	5
G5.	Involved in organization/volunteer work	1	2	3	4	5	1	2	3	4	5
G6.	Being a grandmother	1	2	3	4	5	1	2	3	4	5
G7.	Physically attractive	1	2	3	4	5	1	2	3	4	5
G8.	Being a wife	1	2	3	4	5	1	2	3	4	5
G9.	Healthy	1	2	3	4	5	1	2	3	4	5
G10.	Being a daughter	1	2	3	4	5	1	2	3	4	5
G11.	Intelligent	1	2	3	4	5	1	2	3	4	5
G12.	Able to cope	1	2	3	4	5	1	2	3	4	5
G13.	Spiritual or religious	1	2	3	4	5	1	2	3	4	5
G14.	Outgoing	1	2	3	4	5	1	2	3	4	5
G15.	Independent	1	2	3	4	5	1	2	3	4	5
G16.	Realistic	1	2	3	4	5	1	2	3	4	5
G17.	Active	1	2	3	4	5	1	2	3	4	5
G18.	Loved	1	2	3	4	5	1	2	3	4	5
G19.	Caring	1	2	3	4	5	1	2	3	4	5
G20.	Depressed	1	2	3	4	5	1	2	3	4	5

The following questions apply to persons who are married or living with a partner. Please complete them if you are. If you are not married or living with a partner, please skip to Section I on page 13.

Most persons have disagreements in their relationships. Please indicate, with check marks, on the following list, the extent of agreement or disagreement experienced between you and your partner **DURING THE PAST MONTH**.

		Always Agree	Almost Always Agree	Occasionally Disagree	Frequently Disagree	Almost Always Disagree	Always Disagree
H1.	Handling family finances						
H2.	Matters of recreation						
H3.	Religious matters						
H4.	Demonstration of affection						
H5.	Friends						
H6.	Sex relations						
H7.	Conventionality (correct or proper behavior)						
H8.	Philosophy of life						
H9.	Ways of dealing with parents or in-laws						
H10.	Aims, goals, and things believed important						
H11.	Amount of time spent together						
H12.	Making major decisions						
H13.	Household tasks						
H14.	Leisure time interests and activities						
H15.	Career decisions						

		All of the time	Most of the time	More often than most	Occasionally	Rarely	Never
H16.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?						
H17.	How often do you or your mate leave the house after a fight?						

		All of the time	Most of the time	More often than most	Occasionally	Rarely	Never
H19.	Do you confide in your mate?						
H20.	Do you ever regret that you married (or lived together)?						
H21.	How often do you and your partner quarrel?						
H22.	How often do you and your mate "get on each other's nerves?"						

		Every Day	Almost Every Day	Occasionally	Rarely	Never
H23.	Do you kiss your mate?					

		All of Them	Most of Them	Some of Them	Very few of Them	None of Them
H24.	Do you and your mate engage in outside interests together?					

How often would you say the following events occur between you and your mate?

		Never	Less than once a month	About twice a month	About twice a week	Once a day	More Often
H25.	Have a stimulating exchange of ideas.						
H26.	Laugh together.						
H27.	Calmly discuss something.						
H28.	Work together on a project.						

These are some things couples sometimes agree and sometimes disagree upon. Indicate if either item below caused differences of opinions or were problems in your relationship during the past month. **(Check yes or no).**

H29. Being too tired for sex. ☐ Yes ☐ No

H30. Not showing love. ☐ Yes ☐ No

H31. The following scale represents different degrees of happiness in your relationship. The middle point "happy" represents the degree of happiness of most relationships. **Please circle the statement which best describes the degree of happiness, all things considered, of your relationship.**

Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect
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H32. Please check one of the following statements which best describes how you feel about the **future** of your relationship.

- _____ I want desperately for my relationship to succeed, and would go to almost any length to see that it does.
- _____ I want very much for my relationship to succeed, and will do all I can to see that it does.
- _____ I want very much for my relationship to succeed, and will do my fair share to see that it does.
- _____ It would be very nice if my relationship succeeded, but I can't do much more than I am doing now to help it succeed.
- _____ It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.
- _____ My relationship can never succeed, and there is no more that I can do to keep the relationship going.

I1. In general, would you say your health is:

- ☐ Excellent ☐ Very Good ☐ Good ☐ Fair ☐ Poor

I2. Compared to one year ago, how would you rate your health in general now?(**Check one**)

- ☐ Much better now than one year ago
- ☐ Somewhat better now than one year ago
- ☐ About the same as one year ago
- ☐ Somewhat worse now than one year ago
- ☐ Much worse than one year ago

PLEASE CONTINUE ON TO NEXT PAGE

13. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? *Please mark the appropriate box to indicate your response.*

		<i>YES, limited a lot.</i>	<i>YES, limited a little.</i>	<i>NO, not limited at all.</i>
a.	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.			
b.	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.			
c.	Lifting or carrying groceries.			
d.	Climbing several flights of stairs.			
e.	Climbing one flight of stairs.			
f.	Bending, kneeling, or stooping.			
g.	Walking more than a mile.			
h.	Walking several blocks.			
i.	Walking one block.			
j.	Bathing or dressing yourself.			

14. **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of your **physical** health?

I4a. Cut down the amount of time you spent on work or other activities.

☐ Yes ☐ No

I4b. Accomplished less than you would like.

☐ Yes ☐ No

I4c. Were limited in the kind of work or other activities.

☐ Yes ☐ No

I4d. Had difficulty performing the work or other activities (ie., it took extra effort).

☐ Yes ☐ No

15. **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of any **emotional** problems (such as feeling depressed or anxious)?
- I5a. Cut down the amount of time you spent on work or other activities. ☐ Yes ☐ No
- I5b. Accomplished less than you would like. ☐ Yes ☐ No
- I5c. Didn't do work or other activities as carefully as usual. ☐ Yes ☐ No
16. **During the past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?
- ☐ Not at all ☐ Slightly ☐ Moderately ☐ Quite a bit ☐ Extremely
17. How much bodily pain have you had **during the past 4 weeks**?
- ☐ Not at all ☐ Slightly ☐ Moderately ☐ Quite a bit ☐ Extremely
18. **During the past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?
- ☐ Not at all ☐ Slightly ☐ Moderately ☐ Quite a bit ☐ Extremely
19. These questions are about how you feel and how things have been with you during the past **4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time **during the past 4 weeks**: *Please mark the appropriate box to indicate your response.*

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a.	Did you feel full of pep?						
b.	Have you been a very nervous person?						
c.	Have you felt so down in the dumps that nothing could cheer you up?						
d.	Have you felt calm and peaceful?						
e.	Did you have a lot of energy?						
f.	Have you felt downhearted and blue?						
g.	Have you been a happy person?						
h.	Did you feel tired?						

I10. **During the past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

- ☐ All of the time ☐ Most of the time ☐ A good bit of the time ☐ Some of the time ☐ A little of the time ☐ None of the time

I11. How **TRUE** or **FALSE** is each of the following statements for you?

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get sick a little easier than other people.					
b. I am as healthy as anybody I know.					
c. I expect my health to get worse.					
d. My health is excellent.					

I12. In the **past 6 months**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? ☐ Yes ☐ No

I12a. If **yes**, there was such a two-week period, did your work or relationships suffer?

- ☐ Yes ☐ No

I12b. If **yes**, there was such a two-week period, did you get counseling or psychotherapy?

- ☐ Yes ☐ No

I12c. If there was such a two-week period, did you get medication for this condition?

- ☐ Yes ☐ No

I13. Are you **currently** receiving counseling or psychotherapy or medication for depression or emotional problems? ☐ Yes ☐ No

J1. How often do you have a drink containing alcohol?

- ☐ Never ☐ Monthly or less ☐ Two to four times a month
☐ Two to three times a week ☐ Four or more times a week

J2. How many drinks containing alcohol do you have on a typical day when you are drinking?

- ☐ 1 or 2 ☐ 3 or 4 ☐ 5 or 6 ☐ 7 to 9 ☐ 10 or more

J3. Have you ever felt you should cut down on your drinking?

- ☐ Yes ☐ No

J4. Have people annoyed you by criticizing your drinking?

- ☐ Yes ☐ No

J5. Have you ever felt bad or guilty about drinking?

- ☐ Yes ☐ No

J6. Have you ever taken a drink first thing in the morning to steady your nerves or get rid of a hangover?

- ☐ Yes ☐ No

Listed Below Are Some Symptoms Of Strain That People Sometimes Have. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the **Past Three Months**.*

	<i>Not at all</i>	<i>A little</i>	<i>Quite a bit</i>	<i>Extremely</i>
K1. Suddenly scared for no reason				
K2. Feeling fearful				
K3. Faintness, dizziness, or weakness				
K4. Nervousness or shakiness inside				
K5. Heart pounding or racing				
K6. Trembling				
K7. Feeling tense or keyed up				
K8. Headaches				
K9. Spells of terror or panic				
K10. Feeling restless, can't sit still				
K11. Feeling low in energy--slowed down				
K12. Blaming yourself for things				
K13. Crying easily				
K14. Loss of sexual interest or pleasure				
K15. Poor appetite				
K16. Difficult falling asleep, staying asleep				
K17. Feeling hopeless about the future				
K18. Feeling blue				
K19. Feeling lonely				
K20. Feeling trapped or caught				
K21. Worrying too much about things				
K22. Feeling no interest in things				
K23. Thoughts of ending your life				
K24. Feeling everything is an effort				
K25. Feelings of worthlessness				

- L1. Vividly imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do? Check all of the statements that might apply to you.

_____ I would ask the dentist exactly what he was going to do.
 _____ I would take a tranquilizer or have a drink before going.
 _____ I would try to think about pleasant memories.
 _____ I would want the dentist to tell me when I would feel pain.
 _____ I would try to sleep.
 _____ I would watch all the dentist's movements and listen for the sound of the drill.
 _____ I would watch the flow of water from my mouth to see if it contained blood.
 _____ I would do mental puzzles in my mind.

- L2. Vividly imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do? Check all of the statements that might apply to you.

_____ I would sit by myself and have as many daydreams and fantasies as I could.
 _____ I would stay alert and try to keep myself from falling asleep.
 _____ I would exchange life stories with the other hostages.
 _____ If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing.
 _____ I would watch every movement of my captors and keep an eye on their weapons.
 _____ I would try to sleep as much as possible.
 _____ I would think about how nice it's going to be when I get home.
 _____ I would make sure I knew where every possible exit was.

- L3. Vividly imagine that, due to a large drop in sales, it is rumored that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about lay-off's has been made and will be announced in several days. Check all of the statements that might apply to you.

_____ I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said.
 _____ I would review the list of duties for my present job and try to figure out if I had fulfilled them all.
 _____ I would go to the movies to take my mind off things.
 _____ I would try to remember any arguments or disagreements I might have had with the supervisor that would have lowered his opinion of me.
 _____ I would push all thoughts of being laid off out of my mind.
 _____ I would tell my spouse that I'd rather not discuss my chances of being laid off.
 _____ I would try to think which employees in my department the supervisor might have thought had done the worst job.
 _____ I would continue doing my work as if nothing special was happening.

- L4. Vividly imagine that you are on an airplane, 30 minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced that all is well. Check **all** of the statements that might apply to you.

- _____ I would carefully read the information provided about safety features in the plane and make sure I knew where the emergency exits were.
- _____ I would make small talk with the passenger beside me.
- _____ I would watch the end of the movie, even if I had seen it before.
- _____ I would call for the stewardess and ask her exactly what the problem was.
- _____ I would order a drink or tranquilizer from the stewardess.
- _____ I would listen carefully to the engines for unusual noises and would watch the crew to see if their behavior was out of the ordinary.
- _____ I would talk to the passenger beside me about what might be wrong.
- _____ I would settle down and read a book or magazine or write a letter.

- L5. Please indicate how much you agree with the following statements.

		Strongly Disagree			Strongly Agree	
		1	2	3	4	5
a.	If you don't have your health, you don't have anything.	1	2	3	4	5
b.	There are many things I care about more than my health.	1	2	3	4	5
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5
d.	There is nothing more important than good health.	1	2	3	4	5

PLEASE CONTINUE ON TO NEXT PAGE

Please indicate the extent to which each of the following items describes your current family.

		Strongly Disagree			Strongly Agree	
M1.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5
M2.	In times of crisis we can turn to each other for support.	1	2	3	4	5
M3.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5
M4.	Individuals are accepted for what they are.	1	2	3	4	5
M5.	We avoid discussing our fears and concerns.	1	2	3	4	5
M6.	We can express feelings to each other.	1	2	3	4	5
M7.	There are lots of bad feelings in the family.	1	2	3	4	5
M8.	We feel accepted for what we are.	1	2	3	4	5
M9.	Making decisions is a problem for our family.	1	2	3	4	5
M10.	We are able to make decisions about how to solve problems.	1	2	3	4	5
M11.	We don't get along well together.	1	2	3	4	5
M12.	We confide in each other.	1	2	3	4	5

THANK YOU VERY MUCH.

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WOMEN'S HEALTH STUDY QUESTIONNAIRE

Today's Date _____

ID _____

Background Data

A1. Date of Birth _____Month _____Day _____Year

A2. Ethnic Background: White ☐ Black ☐
 Hispanic ☐ Asian ☐
 Native American ☐ Other ☐

A3. Religion: Catholic ☐ Protestant ☐
 Jewish ☐ Other ☐
 None ☐

A4. Are you currently (**please check one**)? ☐ Single
 ☐ Married
 ☐ Not married, but living in a steady,
 marriage-like relationship
 ☐ Separated
 ☐ Divorced
 ☐ Widowed

A5a. If you **are** currently married, what was the date of your current marriage?

Month _____ Year _____

A5b. Is this your first marriage? Yes ☐ No ☐

A6. How many children do you have? _____

A6a. Number of children living at home _____

A6b. Number who are under age 6 _____

A7. Are you currently working for pay outside the home?

Yes ☐ No ☐

A8. If **yes**, about how many hours per week are you working for pay?

Less than 10	10-20	21-30	31-40	41 or more
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

A9. What is the highest level of education you have completed? (**Check one**)

- ☐ Less than 9th grade
- ☐ Dropped out of high school
- ☐ Completed high school
- ☐ Some college
- ☐ Completed college
- ☐ Some graduate or professional training
- ☐ Completed graduate or professional training

The following two questions are optional, but we hope that you will provide this information.
Please check the appropriate box. (**Check one**)

A10. What is your household's total income? (**Check one**)

- ☐ Less than \$10,000
- ☐ \$10,000 to \$19,999
- ☐ \$20,000 to \$29,999
- ☐ \$30,000 to \$39,999
- ☐ \$40,000 to \$49,999
- ☐ \$50,000 to \$59,999
- ☐ \$60,000 to \$69,999
- ☐ Greater than \$69,999

A11. How many people (adults and children) does this income support? _____

PLEASE CONTINUE ON TO NEXT PAGE

SECTION B

B1. Have you ever been diagnosed with breast cancer? Yes ☐ No ☐

B2. Have you ever been diagnosed with ovarian cancer? Yes ☐ No ☐

B3. Have you ever had any of the following surgical procedures? **(Please check all that apply).**

_____ Lumpectomy (Removal of lump from breast)

_____ Oophorectomy (Removal of ovaries)

_____ Unilateral mastectomy (Removal of one breast)

_____ Hysterectomy (Removal of uterus)

_____ Bilateral mastectomy (Removal of both breasts)

B4. Compared to the average woman, how likely are you to develop breast cancer?

Much Less Likely 1 2 3 4 5 Much More Likely

B5. Compared to other women in your family, how likely are you to develop breast cancer?

Much Less Likely 1 2 3 4 5 Much More Likely

B6. Overall, what do you believe your risk to be of developing breast cancer **in the near future?**

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

B7. Overall, what do you believe your risk to be of developing breast cancer **at some point in your lifetime?**

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

B8. A medical test may soon be available that allows some individual women to learn their risk for developing a form of breast and ovarian cancer that runs in families. Knowing this, what is your intention concerning this test at the present time? **(Please check one response).**

_____ I will definitely take the test immediately when it becomes available.

_____ I will definitely take the test, but I am not sure if immediately.

_____ I will probably take the test immediately when it becomes available.

_____ I will probably take the test, but not immediately.

_____ I am undecided whether I will take the test.

- _____ I will probably not take the test.
_____ I will definitely not take the test.

B9. If you think you will probably or definitely take the test, what are your reasons for doing so?
(Please check all that apply).

- _____ To plan for the future.
_____ To reduce the uncertainty.
_____ To know I have to be more careful about doing breast self examinations and getting regular checkups.
_____ To make decisions about whether to get preventive surgery.
_____ To make decisions about family planning.
_____ To find out the risk that may be transmitted to my children.
_____ Family members want me to get testing.
_____ Other (describe) _____

B10. If you **do not** think you will probably or definitely take the test, what are your reasons for **not** doing so? (Please check all that apply).

- _____ I am happier not knowing.
- _____ It would be too upsetting to learn that I am at high risk for breast cancer.
- _____ I believe I already know what my risk for breast cancer is.
- _____ There would not be much I could do if I found out I was at high risk for breast cancer.
- _____ I do not feel able emotionally to deal with testing.
- _____ Family members do not want me to get testing.
- _____ Risk to my insurance coverage.

B11. If you were to take the test and find out that you **were not** at high risk for breast cancer, what would you expect your reactions to be?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
a.	I would feel wonderful.	1	2	3	4	5
b.	I would feel I had been told what I knew all along.	1	2	3	4	5
c.	I would feel relieved.	1	2	3	4	5
d.	I would not believe the results.	1	2	3	4	5
e.	I would fall apart emotionally.	1	2	3	4	5
f.	I would feel guilty.	1	2	3	4	5
g.	I would still feel anxious.	1	2	3	4	5
h.	I would feel angry.	1	2	3	4	5
i.	I would feel prepared for the future.	1	2	3	4	5
j.	I would feel I had done all I needed to do.	1	2	3	4	5

B12. If you were to take the test and find out that you **were** at high risk for breast cancer, what would you expect your reactions to be?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
a.	I would feel relieved about being more certain.	1	2	3	4	5
b.	I would feel I had been told what I knew all along.	1	2	3	4	5
c.	I would not believe the results.	1	2	3	4	5

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
d.	I would feel guilty.	1	2	3	4	5
e.	I would be depressed.	1	2	3	4	5
f.	I would feel worried about the future.	1	2	3	4	5
g.	I would just fall apart emotionally.	1	2	3	4	5
h.	I would feel anxious.	1	2	3	4	5
i.	I would feel angry.	1	2	3	4	5

B13. To what extent do you agree with the following statements?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
a.	Mammography is effective in the early detection of breast cancer.	1	2	3	4	5
b.	Breast cancer that is detected early is curable.	1	2	3	4	5
c.	Mammography can detect lumps that cannot be felt by you or your doctor.	1	2	3	4	5
d.	If more women went for breast screening, there would be fewer deaths from breast cancer.	1	2	3	4	5
e.	My health is too good to consider thinking that I might get breast cancer.	1	2	3	4	5
f.	If a lump is found in your breast, it is usually too late to do anything about it.	1	2	3	4	5
g.	Whenever I hear of a friend/relative or public figure getting breast cancer I realize that I could get it too.	1	2	3	4	5
h.	If I examine my own breasts regularly, I might find a lump sooner than if I wait to go for screening.	1	2	3	4	5
i.	There are so many things that could happen to me that it is pointless to think about breast cancer.	1	2	3	4	5
j.	Even though it is a good idea, I find examination of my breasts an embarrassment.	1	2	3	4	5
k.	The older I get, the more I think about the possibility of getting breast cancer.	1	2	3	4	5
l.	Going for screening has increased my worry about breast cancer.	1	2	3	4	5
m.	If I was found to have breast cancer, the chances of it being cured are high.	1	2	3	4	5

		<i>Not At All</i>		<i>All The Time</i>		
B15.	How often do you worry about developing breast cancer?	1	2	3	4	5
B16.	To what extent do any worries you have about breast cancer interfere with every day life?	1	2	3	4	5

For the next questions we are interested in how people close to you respond to you when you are in need of support or reassurance. In answering the questions in the **first column**, please keep in mind the female family member at similar risk for breast cancer **with whom you are closest**. Answer the questions in the **second column** keeping in mind **your spouse or intimate partner**. *If you do not have a spouse or intimate partner, please leave the second column blank.* For the **third column**, please keep in mind **another family member or friend to whom you are closest**.

	Female Family Member at Risk for Breast Cancer	Spouse/Partner	Another Family Member/Friend
C1. Was physically present when you needed them.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C2. Told you what he/she did in a similar situation.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C3. Did activities to help you get your mind off things.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C4. Told you that the things you talk about are private--just between the two of you.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C5. Suggested some action you should take.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C6. Comforted you by showing you physical affection.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C7. Listened to you talk about your private feelings.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C8. Agreed that what you want to do is right.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C9. Told you how he/she felt in a similar situation.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C10. Let you know that he/she will always be around if you need assistance.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No

	Female Family Member at Risk for Breast Cancer	Spouse/Partner	Another Family Member/ Friend
C11. Gave you feedback on how you were doing without saying it was good or bad.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C12. Pitched in and helped you do things that needed to get done.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C13. Intruded into your personal feelings and concerns.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C14. Gave you unsolicited advice.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C15. Attempted to make unwanted contact.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C16. Discouraged you from discussing your feelings and concerns.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C17. Minimized your worries or concerns.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C18. Rejected you for displaying emotional upset.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C19. Insisted that you remain upbeat and optimistic.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
C20. Let you down when you were counting on him/her.	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No

C21. Is there anyone in your life with whom you can share your most private feelings without holding back?
☐ yes ☐ no

C21a. **If you are married or living with a partner**, can you share your most private feelings with this partner without holding back?
☐ yes ☐ no

D1. Have any of the events listed happened to you in the past six months? **(Check All That Apply)**

- | | |
|---|--|
| a. <input type="checkbox"/> You retired or were fired or laid off from work. | g. <input type="checkbox"/> A close family member was seriously ill or injured. |
| b. <input type="checkbox"/> You were unemployed and looking for work. | h. <input type="checkbox"/> You had a marital separation or divorce. |
| c. <input type="checkbox"/> Your spouse retired or was fired or laid off from work. | i. <input type="checkbox"/> You had serious troubles with relatives or close friends. |
| d. <input type="checkbox"/> Your spouse was unemployed and looking for work. | j. <input type="checkbox"/> Your spouse had troubles difficulties with relatives or close friends. |
| e. <input type="checkbox"/> You had problems with the police or court. | k. <input type="checkbox"/> A close family member died. |
| f. <input type="checkbox"/> You got into serious financial difficulties. | l. <input type="checkbox"/> A close friend or relative died. |
| | m. <input type="checkbox"/> You were seriously ill or injured. |

For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. Try to be as accurate and as honest as you can, and try not to let your answer to one question influence your answers to other questions. There are no right or wrong answers. We are only interested in your opinions.

		<i>Strongly Disagree</i>		<i>Neutral</i>		<i>Strongly Agree</i>	
E1.	In uncertain times, I usually expect the best.	1	2	3	4	5	
E2.	It's easy for me to relax.	1	2	3	4	5	
E3.	If something can go wrong for me, it will.	1	2	3	4	5	
E4.	I always look on the bright side of things.	1	2	3	4	5	
E5.	I'm always optimistic about my future.	1	2	3	4	5	
E6.	I enjoy my friends a lot.	1	2	3	4	5	
E7.	It's important for me to keep busy.	1	2	3	4	5	
E8.	I hardly ever expect things to go my way.	1	2	3	4	5	
E9.	Things never work out the way I want them to	1	2	3	4	5	
E10.	I don't get upset too easily.	1	2	3	4	5	
E11.	I'm a believer in the idea that "every cloud has a silver lining".	1	2	3	4	5	
E12.	I rarely count on good things happening to me.	1	2	3	4	5	

Below is a list of words which people might use to describe themselves. You are asked to rate them **twice**. First, please indicate for each word how well it describes you and second, how much it matters to you using the following scale.

1	2	3	4	5
Extremely	Very much	Somewhat	Not very well	Not at all

		<i>DESCRIBES ME</i>					<i>MATTERS TO ME</i>				
		1	2	3	4	5	1	2	3	4	5
F1.	Involved in family										
F2.	Aware of being a woman										
F3.	Involved in paid work										
F4.	Being a mother										
F5.	Involved in organization/ volunteer work										
F6.	Being a grandmother										
F7.	Physically attractive										
F8.	Being a wife										
F9.	Healthy										
F10.	Being a daughter										
F11.	Intelligent										
F12.	Able to cope										
F13.	Spiritual or religious										
F14.	Outgoing										
F15.	Independent										
F16.	Realistic										
F17.	Active										
F18.	Loved										
F19.	Caring										
F20.	Depressed										

In the next table, we would like you to first rate how well you think each word will describe you *in the future*, and then, indicate how important it is for you to see yourself this way *in the future*.

1	2	3	4	5
Extremely	Very much	Somewhat	Not very well	Not at all

		<u>WILL DESCRIBE YOU</u>					<u>IMPORTANT FOR YOU TO SEE YOURSELF THIS WAY IN FUTURE</u>				
		1	2	3	4	5	1	2	3	4	5
G1.	Involved in family	1	2	3	4	5	1	2	3	4	5
G2.	Aware of being a woman	1	2	3	4	5	1	2	3	4	5
G3.	Involved in paid work	1	2	3	4	5	1	2	3	4	5
G4.	Being a mother	1	2	3	4	5	1	2	3	4	5
G5.	Involved in organization/ volunteer work	1	2	3	4	5	1	2	3	4	5
G6.	Being a grandmother	1	2	3	4	5	1	2	3	4	5
G7.	Physically attractive	1	2	3	4	5	1	2	3	4	5
G8.	Being a wife	1	2	3	4	5	1	2	3	4	5
G9.	Healthy	1	2	3	4	5	1	2	3	4	5
G10.	Being a daughter	1	2	3	4	5	1	2	3	4	5
G11.	Intelligent	1	2	3	4	5	1	2	3	4	5
G12.	Able to cope	1	2	3	4	5	1	2	3	4	5
G13.	Spiritual or religious	1	2	3	4	5	1	2	3	4	5
G14.	Outgoing	1	2	3	4	5	1	2	3	4	5
G15.	Independent	1	2	3	4	5	1	2	3	4	5
G16.	Realistic	1	2	3	4	5	1	2	3	4	5
G17.	Active	1	2	3	4	5	1	2	3	4	5
G18.	Loved	1	2	3	4	5	1	2	3	4	5
G19.	Caring	1	2	3	4	5	1	2	3	4	5
G20.	Depressed	1	2	3	4	5	1	2	3	4	5

The following questions apply to persons who are married or living with a partner. Please complete them if you are. If you are not married or living with a partner, please skip to Section I on page 13.

Most persons have disagreements in their relationships. Please indicate, with check marks, on the following list, the extent of agreement or disagreement experienced between you and your partner **DURING THE PAST MONTH**.

		Always Agree	Almost Always Agree	Occasionally Disagree	Frequently Disagree	Almost Always Disagree	Always Disagree
H1.	Handling family finances						
H2.	Matters of recreation						
H3.	Religious matters						
H4.	Demonstration of affection						
H5.	Friends						
H6.	Sex relations						
H7.	Conventionality (correct or proper behavior)						
H8.	Philosophy of life						
H9.	Ways of dealing with parents or in-laws						
H10.	Aims, goals, and things believed important						
H11.	Amount of time spent together						
H12.	Making major decisions						
H13.	Household tasks						
H14.	Leisure time interests and activities						
H15.	Career decisions						

		All of the time	Most of the time	More often than most	Occasionally	Rarely	Never
H16.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?						
H17.	How often do you or your mate leave the house after a fight?						
H18.	In general, how often do you think that things between you and your partner are going well?						
H19.	Do you confide in your mate?						
H20.	Do you ever regret that you married (or lived together)?						
H21.	How often do you and your partner quarrel?						
H22.	How often do you and your mate "get on each other's nerves?"						

		Every Day	Almost Every Day	Occasionally	Rarely	Never
H23.	Do you kiss your mate?					

		All of Them	Most of Them	Some of Them	Very few of Them	None of Them
H24.	Do you and your mate engage in outside interests together?					

How often would you say the following events occur between you and your mate?

		Never	Less than once a month	About twice a month	About twice a week	Once a day	More Often
H25.	Have a stimulating exchange of ideas.						
H26.	Laugh together.						
H27.	Calmly discuss something.						
H28.	Work together on a project.						

These are some things couples sometimes agree and sometimes disagree upon. Indicate if either item below caused differences of opinions or were problems in your relationship during the past month. **(Check yes or no).**

H29. Being too tired for sex. ☐ Yes ☐ No

H30. Not showing love. ☐ Yes ☐ No

H31. The following scale represents different degrees of happiness in your relationship. The middle point "happy" represents the degree of happiness of most relationships. Please circle the statement which best describes the degree of happiness, all things considered, of your relationship.

Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect
----------------------	-------------------	---------------------	-------	---------------	--------------------	---------

H32. Please check one of the following statements which best describes how you feel about the **future** of your relationship.

- _____ I want desperately for my relationship to succeed, and would go to almost any length to see that it does.
- _____ I want very much for my relationship to succeed, and will do all I can to see that it does.
- _____ I want very much for my relationship to succeed, and will do my fair share to see that it does.
- _____ It would be very nice if my relationship succeeded, but I can't do much more than I am doing now to help it succeed.
- _____ It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.
- _____ My relationship can never succeed, and there is no more that I can do to keep the relationship going.

SECTION I

11. In general, would you say your health is:
☐ Excellent ☐ Very Good ☐ Good ☐ Fair ☐ Poor

12. Compared to one year ago, how would you rate your health in general now?**(Check one)**

- ☐ Much better now than one year ago
- ☐ Somewhat better now than one year ago
- ☐ About the same as one year ago
- ☐ Somewhat worse now than one year ago
- ☐ Much worse than one year ago

13. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? *Please mark the appropriate box to indicate your response.*

		<i>YES, limited a lot.</i>	<i>YES, limited a little.</i>	<i>NO, not limited at all.</i>
a.	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.			
b.	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.			
c.	Lifting or carrying groceries.			
d.	Climbing several flights of stairs.			
e.	Climbing one flight of stairs.			
f.	Bending, kneeling, or stooping.			
g.	Walking more than a mile.			
h.	Walking several blocks.			
i.	Walking one block.			
j.	Bathing or dressing yourself.			

14. **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of your **physical** health?

- Cut down the amount of time you spent on work or other activities.
☐ Yes ☐ No
- Accomplished less than you would like.
☐ Yes ☐ No
- Were limited in the kind of work or other activities.
☐ Yes ☐ No
- Had difficulty performing the work or other activities (for example, it took extra effort).
☐ Yes ☐ No

15. **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of any **emotional** problems (such as feeling depressed or anxious)?

- a. Cut down the amount of time you spent on work or other activities. ☐ Yes ☐ No
- b. Accomplished less than you would like. ☐ Yes ☐ No
- c. Didn't do work or other activities as carefully as usual. ☐ Yes ☐ No

16. **During the past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

- ☐ Not at all ☐ Slightly ☐ Moderately ☐ Quite a bit ☐ Extremely

17. How much bodily pain have you had **during the past 4 weeks**?

- ☐ Not at all ☐ Slightly ☐ Moderately ☐ Quite a bit ☐ Extremely

18. **During the past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?

- ☐ Not at all ☐ Slightly ☐ Moderately ☐ Quite a bit ☐ Extremely

19. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time **during the past 4 weeks**: *Please mark the appropriate box to indicate your response.*

		<i>All of the time</i>	<i>Most of the time</i>	<i>A good bit of the time</i>	<i>Some of the time</i>	<i>A little of the time</i>	<i>None of the time</i>
a.	Did you feel full of pep?						
b.	Have you been a very nervous person?						
c.	Have you felt so down in the dumps that nothing could cheer you up?						
d.	Have you felt calm and peaceful?						
e.	Did you have a lot of energy?						
f.	Have you felt downhearted and blue?						

		<i>All of the time</i>	<i>Most of the time</i>	<i>A good bit of the time</i>	<i>Some of the time</i>	<i>A little of the time</i>	<i>None of the time</i>
g.	Have you been a happy person?						
h.	Did you feel tired?						

I10. **During the past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

☐ All of the time ☐ Most of the time ☐ A good bit of the time ☐ Some of the time ☐ A little of the time ☐ None of the time

I11. How **TRUE** or **FALSE** is each of the following statements for you?

	<i>Definitely True</i>	<i>Mostly True</i>	<i>Don't Know</i>	<i>Mostly False</i>	<i>Definitely False</i>
a. I seem to get sick a little easier than other people.					
b. I am as healthy as anybody I know.					
c. I expect my health to get worse.					
d. My health is excellent.					

I12. In the **past 6 months**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun?

☐ **YES** ☐ **NO**

a. If **yes**, there was such a two-week period, did your work or relationships suffer?

☐ yes ☐ no

b. If **yes**, there was such a two-week period, did you get counseling or psychotherapy?

☐ yes ☐ no

c. If there was such a two-week period, did you get medication for this condition?

☐ yes ☐ no

I13. Are you **currently** receiving counseling or psychotherapy or medication for depression or emotional problems?

☐ **YES** ☐ **NO**

- J1. How often do you have a drink containing alcohol?
☐ Never ☐ Monthly or less ☐ Two to four times a month
☐ Two to three times a week ☐ Four or more times a week
- J2. How many drinks containing alcohol do you have on a typical day when you are drinking?
☐ 1 or 2 ☐ 3 or 4 ☐ 5 or 6 ☐ 7 to 9 ☐ 10 or more
- J3. Have you ever felt you should cut down on your drinking?
☐ YES ☐ NO
- J4. Have people annoyed you by criticizing your drinking?
☐ YES ☐ NO
- J5. Have you ever felt bad or guilty about drinking?
☐ YES ☐ NO
- J6. Have you ever taken a drink first thing in the morning to steady your nerves or get rid of a hangover?
☐ YES ☐ NO

Listed Below Are Some Symptoms Of Strain That People Sometimes Have. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the Past Three Months.*

	Not at all	A little	Quite a bit	Extremely
K1. Suddenly scared for no reason				
K2. Feeling fearful				
K3. Faintness, dizziness, or weakness				
K4. Nervousness or shakiness inside				
K5. Heart pounding or racing				
K6. Trembling				
K7. Feeling tense or keyed up				
K8. Headaches				
K9. Spells of terror or panic				
K10. Feeling restless, can't sit still				
K11. Feeling low in energy--slowed down				
K12. Blaming yourself for things				
K13. Crying easily				

K14. Loss of sexual interest or pleasure				
K15. Poor appetite				
K16. Difficult falling asleep, staying asleep				
K17. Feeling hopeless about the future				
K18. Feeling blue				
K19. Feeling lonely				
K20. Feeling trapped or caught				
K21. Worrying too much about things				
K22. Feeling no interest in things				
K23. Thoughts of ending your life				
K24. Feeling everything is an effort				
K25. Feelings of worthlessness				

L1. Vividly imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do? Check all of the statements that might apply to you.

- ☐ I would ask the dentist exactly what he was going to do.
- ☐ I would take a tranquilizer or have a drink before going.
- ☐ I would try to think about pleasant memories.
- ☐ I would want the dentist to tell me when I would feel pain.
- ☐ I would try to sleep.
- ☐ I would watch all the dentist's movements and listen for the sound of the drill.
- ☐ I would watch the flow of water from my mouth to see if it contained blood.
- ☐ I would do mental puzzles in my mind.

L2. Vividly imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do? Check all of the statements that might apply to you.

- ☐ I would sit by myself and have as many daydreams and fantasies as I could.
- ☐ I would stay alert and try to keep myself from falling asleep.
- ☐ I would exchange life stories with the other hostages.
- ☐ If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing.
- ☐ I would watch every movement of my captors and keep an eye on their weapons.
- ☐ I would try to sleep as much as possible.
- ☐ I would think about how nice it's going to be when I get home.
- ☐ I would make sure I knew where every possible exit was.

L3. Please indicate how much you agree with the following statements.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
		1	2	3	4	5
a.	If you don't have your health, you don't have anything.	1	2	3	4	5
b.	There are many things I care about more than my health.	1	2	3	4	5
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5
d.	There is nothing more important than good health.	1	2	3	4	5

Please indicate the extent to which each of the following items describes your current family.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
		1	2	3	4	5
M1.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5
M2.	In times of crisis we can turn to each other for support.	1	2	3	4	5
M3.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5
M4.	Individuals are accepted for what they are.	1	2	3	4	5
M5.	We avoid discussing our fears and concerns.	1	2	3	4	5
M6.	We can express feelings to each other.	1	2	3	4	5
M7.	There are lots of bad feelings in the family.	1	2	3	4	5
M8.	We feel accepted for what we are.	1	2	3	4	5
M9.	Making decisions is a problem for our family.	1	2	3	4	5
M10.	We are able to make decisions about how to solve problems.	1	2	3	4	5
M11.	We don't get along well together.	1	2	3	4	5
M12.	We confide in each other.	1	2	3	4	5

THANK YOU VERY MUCH.

CSID -

INTERVIEWER _____

Use of SCID modules**Depression.**

We will be assessing **current major depressive episode** using the module from the SCID, A1-A5.

(add to A2, item 3: Is that a significant weight loss for you?)

(add to A2, item 4: **Insomnia:** - more than 60 minutes falling asleep
 - more than 30 minutes midnight awakening
 - more than 60 minutes early morning awakening

Hypersomnia: - very early to bed
 - very late rising
 - extended naps (greater than 2 hours)

We then assess **past major depressive episode**, A12-A18.

We then assess **current dysthymia**, A38-A43.

Substance Use Disorders.

We assess **Lifetime Alcohol Abuse/Dependence** using the SCID, E1-E7.

Anxiety Disorders.

We assess **current generalized anxiety disorder**, F31-F35.

We then assess **current mixed anxiety disorder**, J5-J8.

NOTE: Modules for the following pages have not been completed

A-6 through A-11
A-19 through A-37
A-42
F-1 through F-30
J-1 through J-4

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Women's Health Study

Telephone Questionnaire

Revised 4/19/96

Introduction/Confidentiality Statement

Hello. My name is _____. I'm calling from the Women's Health Study. Thank you for returning your questionnaire. As we had mentioned, we have some questions about your opinions, experiences, and feelings related to cancer and genetic testing, and about your mood. You may have provided some of this information already, but it is important that we update our records. Before we start, I would like to assure you that your name was picked randomly from the pool of people that had volunteered for the genetic studies. We do not have any new information about your status. I would also like to assure you that this interview is confidential and completely voluntary. If we should come to any questions which you do not want to answer or which do not apply to you, just let me know and we will go on to the next question. For quality control purposes, we would like to tape record this interview if that is all right with you. ...May we begin?

Date_____

Length of IW_____

Length of Edit_____

Interviewer_____

CANCER STATUS:

- 1a. I understand that you (have/have not) been diagnosed with breast cancer.

1. Have Been Diagnosed	5. Have Not
------------------------	-------------

	Breast Cancer Positive
	Ovarian Cancer Positive

IF R INDICATES "HAVE BEEN DIAGNOSED" TO 1a:

- 1b. When were you diagnosed?

DATE: _____ (month/year)

- 1c. On a scale from 1 to 5, with 1 being "not at all distressing" and 5 being "very distressing," how distressed were you by this diagnosis?

Not At All Distressing			Very Distressing	
1	2	3	4	5

- 2a. I understand that you (have/have not) been diagnosed with ovarian cancer.

1. Have Been Diagnosed	5. Have Not
------------------------	-------------

IF R INDICATES "HAVE BEEN DIAGNOSED" TO 2a:

- 2b. When were you diagnosed?

DATE: _____ (month/year)

- 2c. On a scale from 1 to 5, with 1 being "not at all distressing" and 5 being "very distressing," how distressed were you by this diagnosis?

Not At All Distressing			Very Distressing	
1	2	3	4	5

IF R INDICATES "HAVE BEEN DIAGNOSED" TO EITHER 1a OR 2a OR BOTH:

- 2d. Have you ever had a second diagnosis of cancer? E.G. AFTER REMISSION, ETC.

1. Yes	5. No
--------	-------

IF R INDICATES "YES" TO 2d:

2e. When did you receive this second diagnosis?

DATE: _____(month/year)

2f. On a scale from 1 to 5, with 1 being "not at all distressing" and 5 being "very distressing," how distressed were you by this diagnosis?

Not At All Distressing			Very Distressing	
1	2	3	4	5

IF R INDICATES "YES" or "HAVE BEEN DIAGNOSED" TO 1a, 2a, OR 2d:

2g. Is your cancer currently in remission?

1. Yes	5. No
--------	-------

IF R INDICATES "YES" TO 2g:

2h. How long has your cancer been in remission?

TIME: _____(months)

2i. On a scale from 1 to 5, how distressing is it to be a member of a family that may be at risk for breast cancer?

Not At All Distressing			Very Distressing	
1	2	3	4	5

A test is now available which allows women in high-risk families to find out if they (personally) have the alteration(s) of a gene (BRCA1) associated with increased risk for breast and ovarian cancer.

2j. On a scale from 1 to 5, how distressing is it to be given the opportunity to be tested for this gene?

Not At All Distressing			Very Distressing	
1	2	3	4	5

2k. On a scale from 1 to 5, 1 being "not at all," and 5 being "very much," to what extent do you welcome the opportunity to be tested?

Not At All			Very Much	
1	2	3	4	5

- 2l. On a scale from 1 to 5, with 1 being "not at all distressing," and 5 being "very distressing," how distressing would it be to have the test and discover that you have the altered gene that is associated with an increased risk for breast and ovarian cancer?

Not At All Distressing			Very Distressing	
1	2	3	4	5

- 2m. Using the same scale, how distressing would it be to have the test and discover that you do not have the altered gene?

Not At All Distressing			Very Distressing	
1	2	3	4	5

FOR QUESTIONS 3-5b, INDICATE THE NUMBER OF RELATIVES AFFECTED BY CANCER - ENTER ZERO FOR NO CANCER DIAGNOSIS IN A CATEGORY

		Mother	Sister(s)	Daughter(s)	First Aunt(s)	Grandmother(s)	First Cousin(s)
3.	Which of your relatives has had breast cancer?						
4.	Which of your relatives has had ovarian cancer?						
5a.	Have any of your relatives died of breast cancer?						
5b.	Have any of your relatives died of ovarian cancer?						

NOT INCLUDING
GREAT-
GRANDMOTHERS

RELATIVES AFFECTED BY CANCER:

REPEAT THIS SECTION (QUESTIONS 0-10) FOR EACH RELATIVE R INDICATES AFFECTED BY CANCER

Now I am going to ask you about your experiences with cancer among your close relatives.

Let's Start with _____(relationship)

0. Is she from your mother or your father's side of the family?

Mother's	Father's
1	2

1. When was she diagnosed?

DATE: _____(year)

1a. On a scale from 1 to 5, how distressed were you by her diagnosis?

Not At All Distressed		Very Distressed		
1	2	3	4	5

Didn't Know IF VOL.
6

2. Is she alive?

1. Yes	5. No
--------	-------

IF R ANSWERS "NO" TO 2:

2a. Did she die of the cancer or something related to it?
SCORE R's BELIEF

1. Yes	5. No
--------	-------

IF R ANSWERS "YES" To 2a:

2b. When did she die?

DATE: _____(year)

2c. How old was she when she died?

AGE: _____(years)

2d. How old were you when she died?

AGE: _____(years)

2e. On a scale from 1 to 5, how distressed were you by this news?

Not At All Distressed			Very Distressed	
1	2	3	4	5

Didn't Know IF VOL.
6

3. What treatment did she receive? SCORE EACH SURGERY SEPARATELY

Treatment:	1. Yes	5. No
A. Lumpectomy		
B. Unilateral Mastectomy		
C. Bilateral Mastectomy		
D. Oophorectomy (ovaries removed)		
E. Hysterectomy		
F. Chemotherapy		
G. Radiation		
H. Hormonal Therapy		
I. Immunotherapy		
J. Don't Know		
K. Other		
L. None		

IF BOTH BREASTS REMOVED IN
TWO SEPARATE SURGERIES
SCORE YES FOR UNILATERAL
AND YES FOR BILATERAL

On a scale of 1 to 5, with 1 being "not at all" and 5 being "very much,"

		Not At All				Very Much	Didn't Know IF VOL.
4.	At the time of the illness, how (emotionally) close were you to your (relative)?	1	2	3	4	5	6

On a scale of 1 to 5, with 1 being "not at all" and 5 being "very much",

5. At the time of her illness, how aware were you of the following aspects of your (relative's) condition?

	Not at All				Very Much	Didn't Know If Vol
A. Diagnosis	1	2	3	4	5	6
B. Course of illness	1	2	3	4	5	6
C. Prognosis (what could be expected)	1	2	3	4	5	6
D. Her pain or suffering	1	2	3	4	5	6
E. Side effects of treatment	1	2	3	4	5	6
F. Impairment (not being able to do what she once did) and disruption of her life	1	2	3	4	5	6
G. How involved were you in the treatment and care of your (relative)?	1	2	3	4	5	6

6. At the time of her illness, did you help care for her in any of the following ways?

	1. Yes	5. No
A. Accompanied to appointments		
B. Visited at hospital		
C. Did chores for her		
D. Provided comfort and emotional support		

On a scale of 1 to 5, with 1 being "not at all" and 5 being "very much,"

	Not At All				Very Much	Didn't Know IF VOL.
7. At that time, to what extent did you talk with her about her experience?	1	2	3	4	5	6
8. At that time, how upsetting was her experience with cancer for you? [OVERALL]	1	2	3	4	5	6

	Much More Distant	A Little More Distant	No Change	A Little Closer	A Lot Closer
9. At that time, how did your (relative's) illness affect your relationship with other family members? Did it make you...[READ OPTIONS]	1	2	3	4	5

On a scale of 1 to 5, with 1 being "not at all" and 5 being "very much,"

	Not At All				Very Much	Didn't Know IF VOL.
10. How much has your experience with your (relative) affected the way you think about your own risk for cancer and options for dealing with it? [CURRENTLY]	1	2	3	4	5	6

REPEAT QUESTIONS 0-10 (STARTING ON PAGE 5) FOR ANY ADDITIONAL RELATIVES

11. Now I'd like to find out how you keep up with new information about breast cancer (including prevention, detection, and treatment). I'm going to read you a list of sources; On a scale from 1 to 5, with 1 being "not at all" and 5 being "very much," how much do you rely on... REPEAT AS NECESSARY

	Not At All				Very Much
a. Your OB/GYN	1	2	3	4	5
b. Your family physician	1	2	3	4	5
c. Another physician (Specialty_____)	1	2	3	4	5
d. Family Members [WHO GAVE INFO]	1	2	3	4	5
e. Friends [WHO GAVE INFO]	1	2	3	4	5
f. Newspapers, television, and radio	1	2	3	4	5
g. Popular women's magazines	1	2	3	4	5
h. Other (specify_____)	1	2	3	4	5

READ OPTIONS

	Not At All	A Little	Somewhat	A Great Deal
12. How much do you watch for new information in the media (newspaper, magazines, television, radio)?	1	2	3	4
13. How much do you try to avoid this information in the media?	1	2	3	4
14. How much confidence do you have in the accuracy of such information in the media?	1	2	3	4

15bi. Are you aware of the gene (BRCA1) associated with increased risk for early onset breast cancer?

1. Yes	5. No
--------	-------

IF R ANSWERS "YES" TO 15b:

	Hopeful	Relieved	Anxious or Fearful	Depressed
15c. Which of the following best describes how you felt when you heard about the discovery of this gene? READ OPTIONS - R MAY CHOOSE ONLY ONE	1	2	3	4

IF R ANSWERS "YES" TO 15b:

	Not At All	A Little	Somewhat	A Great Deal
15d. How much did you discuss this development with your mother and/or your sisters? READ OPTIONS	1	2	3	4
15e. IF R IS MARRIED/PARTNERED: How much have you discussed this development with your (spouse/partner)? READ OPTIONS	1	2	3	4
15f. IF R HAS CHILDREN: How much have you discussed this development with your children? READ OPTIONS	1	2	3	4

15g. IF R IS CANCER POSITIVE:

Women who are living with breast cancer report various levels of distress.
How often do you feel distressed about living with breast cancer?

IF R IS CANCER NEGATIVE:

Women who are at risk for breast cancer report various levels of distress.
How often do you feel distressed about your risk for breast cancer?

READ OPTIONS

Never	Rarely	Sometimes	Often
1	2	3	4

15h. Thinking about your family's risk for breast cancer and your own diagnosis/risk, what has been the most distressing part?

15i. On a scale from 1 to 5, how distressing is this?

Not At All Distressing			Very Distressing	
1	2	3	4	5

FOR WOMEN WITH LIVING SISTERS:
SKIP IF R HAS NO LIVING SISTERS

Now I'm going to ask some questions about your relationship with your sisters.

16a. IF R IS CANCER POSITIVE:

How often do you discuss living with breast cancer with your sisters?

IF R IS CANCER NEGATIVE:

How often do you discuss your risk for breast cancer with your sisters?

READ OPTIONS

Never	Rarely	Sometimes	Often
1	2	3	4

IF R ANSWERS "NEVER" TO 16a, DO NOT ASK 16b-d

16b. When you have these discussions, who generally initiates them?

You	Your Sisters	Equally [IF VOLUNTEERED]
1	2	3

16c. How satisfied are you with these discussions?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

16d. What is helpful to you when talking with your sisters about your risk for breast cancer?
SCORE ALL THAT APPLY - R CAN CHOOSE MORE THAN ONE - SCORE WHAT IS CURRENTLY HELPFUL, NOT WHAT THEY BELIEVE MIGHT BE HELPFUL

	1. Yes	5. No
1. Receiving new information.		
2. The opportunity to express your feelings.		
3. Receiving comfort or being taken care of.		
4. Feeling understood.		
5. Knowing you are not alone.		

16e. Overall, how important is your sister's opinion in your decision whether or not to be tested for the breast cancer gene?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

- 16f. In making decisions about what to do to reduce your risk of breast cancer in the future, how important is your sister's opinion?
IF R INSISTS THAT THERE ARE NO MORE DECISIONS TO BE MADE, CODE 1

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

- 16g. Considering **only the positive feelings** you have toward your sisters, and **ignoring the negative ones**, please rate how positive these feelings are. Use a scale of 1 to 10, with 1 being "not at all positive" and 10 being "extremely positive." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Positive								Extremely Positive	
1	2	3	4	5	6	7	8	9	10

- 16h. Considering **only the negative feelings** you have toward your sisters, and **ignoring the positive ones**, please rate how negative these feelings are. Use a scale of 1 to 10, with 1 being "not at all negative" and 10 being "extremely negative." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Negative								Extremely Negative	
1	2	3	4	5	6	7	8	9	10

FOR WOMEN WITH LIVING MOTHERS:
SKIP IF R's MOTHER IS NOT LIVING

Now I am going to ask some questions about your relationship with your mother.

- 17a. IF R IS CANCER POSITIVE:
How often do you discuss living with breast cancer with your mother?

IF R IS CANCER NEGATIVE:
How often do you discuss your risk for breast cancer with your mother?

READ OPTIONS

Never	Rarely	Sometimes	Often
1	2	3	4

IF R ANSWERS "NEVER" TO 17a, DO NOT ASK 17b-d

17b. When you have these discussions, who generally initiates them?

You	Your Mother	Equally [IF VOLUNTEERED]
1	2	3

17c. How satisfied are you with these discussions?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

17d. What is helpful to you when talking with your mother about your risk for breast cancer?
SCORE ALL THAT APPLY - R CAN CHOOSE MORE THAN ONE - SCORE WHAT IS CURRENTLY HELPFUL, NOT WHAT THEY BELIEVE MIGHT BE HELPFUL

	1. Yes	5. No
1. Receiving new information.		
2. The opportunity to express your feelings.		
3. Receiving comfort or being taken care of.		
4. Feeling understood.		
5. Knowing you are not alone.		

17e. Overall, how important is your mother's opinion in your decision whether or not to be tested for the breast cancer gene?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

- 17f. In making decisions about what to do to reduce your risk of breast cancer in the future, how important is your mother's opinion?
IF R INSISTS THAT THERE ARE NO MORE DECISIONS TO BE MADE, CODE 1

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

- 17g. Considering **only the positive feelings** you have toward your mother, and **ignoring the negative ones**, please rate how positive these feelings are. Use a scale of 1 to 10, with 1 being "not at all positive" and 10 being "extremely positive." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Positive								Extremely Positive	
1	2	3	4	5	6	7	8	9	10

- 17h. Considering **only the negative feelings** you have toward your mother, and **ignoring the positive ones**, please rate how negative these feelings are. Use a scale of 1 to 10, with 1 being "not at all negative" and 10 being "extremely negative." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Negative								Extremely Negative	
1	2	3	4	5	6	7	8	9	10

FOR WOMEN WHO ARE MARRIED OR LIVING WITH A PARTNER:
SKIP IF R IS NOT MARRIED/PARTNERED

Now I am going to ask you some questions about your relationship with your (husband/partner).

- 18a. IF R IS CANCER POSITIVE:
How often do you discuss living with breast cancer with your husband/partner?

IF R IS CANCER NEGATIVE:
How often do you discuss your risk for breast cancer with your husband/partner?

READ OPTIONS

Never	Rarely	Sometimes	Often
1	2	3	4

IF R ANSWERS "NEVER" TO 18a, DO NOT ASK 18b-d

- 18b. When you have these discussions, who generally initiates them?

You	Your Husband/ Partner	Equally [IF VOLUNTEERED]
1	2	3

- 18c. How satisfied are you with these discussions?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

- 18d. What is helpful to you when talking with your husband/partner about your risk for breast cancer?
SCORE ALL THAT APPLY - R CAN CHOOSE MORE THAN ONE - SCORE WHAT IS CURRENTLY HELPFUL, NOT WHAT THEY BELIEVE MIGHT BE HELPFUL

	1. Yes	5. No
1. Receiving new information.		
2. The opportunity to express your feelings.		
3. Receiving comfort or being taken care of.		
4. Feeling understood.		
5. Knowing you are not alone.		

- 18e. Overall, how important is your husband/partner's opinion in your decision whether or not to be tested for the breast cancer gene?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

- 18f. In making decisions about what to do to reduce your risk of breast cancer in the future, how important is your (husband's/partner's) opinion?
IF R INSISTS THAT THERE ARE NO MORE DECISIONS TO BE MADE, CODE 1

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

- 18g. Considering **only the positive feelings** you have toward your husband/partner, and **ignoring the negative ones**, please rate how positive these feelings are. Use a scale of 1 to 10, with 1 being "not at all positive" and 10 being "extremely positive." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Positive								Extremely Positive	
1	2	3	4	5	6	7	8	9	10

- 18h. Considering **only the negative feelings** you have toward your husband/partner, and **ignoring the positive ones**, please rate how negative these feelings are. Use a scale of 1 to 10, with 1 being "not at all negative" and 10 being "extremely negative." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Negative								Extremely Negative	
1	2	3	4	5	6	7	8	9	10

FOR WOMEN WITH LIVING DAUGHTER/S:
SKIP IF R HAS NO LIVING DAUGHTER/S

Now I am going to ask you some questions about your relationship with your daughter/s.

- 19i. What are the ages of your daughters?

_____	_____	_____
_____	_____	_____
_____	_____	_____

- 19ii. In general, do you discuss family history and risk for breast cancer with your daughter/s?

1. Yes	5. No
--------	-------

- 19e. Overall, how important is/are your daughters' opinion in your decision whether or not to be tested for the breast cancer gene?

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

- 19f. In making decisions about what to do to reduce your risk of breast cancer in the future, how important is/are your daughter's opinion/s?
IF R INSISTS THAT THERE ARE NO MORE DECISIONS TO BE MADE, CODE 1

READ OPTIONS

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

- 19g. Considering **only the positive feelings** you have toward your daughters, and **ignoring the negative ones**, please rate how positive these feelings are. Use a scale of 1 to 10, with 1 being "not at all positive" and 10 being "extremely positive." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Positive								Extremely Positive	
1	2	3	4	5	6	7	8	9	10

- 19h. Considering **only the negative feelings** you have toward your daughters, and **ignoring the positive ones**, please rate how negative these feelings are. Use a scale of 1 to 10, with 1 being "not at all negative" and 10 being "extremely negative." SCORE GENERAL FEELING TOWARD PERSON, NOT JUST REGARDING CANCER

Not At All Negative								Extremely Negative	
1	2	3	4	5	6	7	8	9	10

FOR WOMEN WITH CHILDREN:
SKIP IF R HAS NO CHILDREN

- 19iii. If you should choose to obtain genetic testing, do you intend to inform your children of the results?

1. Yes	5. No	7. Undecided [IF VOLUNTEERED]
--------	-------	----------------------------------

FOR ALL WOMEN:

20. If you were to find that you were a carrier for BRCA1, the gene for increased risk of breast cancer, what options would you consider?

[DONE]

CSID -

INTERVIEWER _____

Use of SCID modules

Depression.

We will be assessing **current major depressive episode** using the module from the SCID, A1-A5.

(add to A2, item 3: Is that a significant weight loss for you?)

(add to A2, item 4: Insomnia: - more than 60 minutes falling asleep
 - more than 30 minutes midnight awakening
 - more than 60 minutes early morning awakening

 Hypersomnia: - very early to bed
 - very late rising
 - extended naps (greater than 2 hours)

We then assess **past major depressive episode**, A12-A18.

We then assess **current dysthymia**, A38-A43.

Substance Use Disorders.

We assess **Lifetime Alcohol Abuse/Dependence** using the SCID, E1-E7.

Anxiety Disorders.

We assess **current generalized anxiety disorder**, F31-F35.

We then assess **current mixed anxiety disorder**, J5-J8.

IN THIS SECTION, MAJOR DEPRESSIVE, MANIC HYPOMANIC EPISODES, DYSTHYMIC DISORDER, MOOD DISORDER DUE TO A GENERAL MEDICAL CONDITION, SUBSTANCE-INDUCED MOOD DISORDER, AND EPISODE SPECIFIERS ARE EVALUATED. MAJOR DEPRESSIVE DISORDER AND BIPOLAR DISORDERS ARE DIAGNOSED IN MODULE D.

CURRENT MAJOR DEPRESSIVE EPISODE

Now I am going to ask you
some more questions about your
mood.

In the last month...

...has there been a period of
time when you were feeling
depressed or down most of the
day nearly every day? (What
was that like?)

IF YES: How long did
it last? (As long as two
weeks?) When did it
begin?

...what about having little
interest or pleasure in doing
things?

IF YES: Was it nearly
every day? How long
did it last? (As long as
two weeks?)

MDE CRITERIA

A. Five (or more) of the
following symptoms have been
present during the same two
week period and represent a
change from previous
functioning; at least one of the
symptoms is either (1)
depressed mood or (2) loss of
interest or pleasure.

(1) depressed mood most of
the day, nearly every day, as
indicated either by
subjective report (e.g., feels
sad or empty) or
observation made by others
(e.g., appears tearful). Note:
in children and adolescents,
can be irritable mood.

? 1 2 3 A1

(2) markedly diminished
interest or pleasure in all, or
almost all, activities most of
the day, nearly every day (as
indicated either by
subjective account of
observation made by others)

? 1 2 3 A2

IF NEITHER ITEM (1) NOR
ITEM (2) IS CODED "3," GO
TO *PAST MAJOR
DEPRESSIVE EPISODE*,
A.12

NOTE: WHEN RATING THE
FOLLOWING ITEMS, CODE
"1" IF CLEARLY DUE TO A
GENERAL MEDICAL
CONDITION, MOOD-
INCONGRUENT DELUSIONS
OR HALLUCINATIONS

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

FOR THE FOLLOWING QUESTIONS, FOCUS ON THE WORST TWO WEEKS IN THE PAST MONTH
(OR ELSE THE PAST TWO WEEKS IF EQUALLY DEPRESSED FOR THE ENTIRE MONTH)

During this (TWO WEEK
PERIOD)...

..did you lose or gain any
weight? (How much?) (Were
you trying to lose weight?)

IF NO: How was your
appetite? (What about
compared to your usual
appetite?) (Did you have to
force yourself to eat?) (Eat
[less/more] than usual?)
(Was that nearly every day?)

(3) significant weight loss when
not dieting, or weight gain (e.g.,
a change of more than 5% of
body weight in a month) or
decrease or increase in appetite
nearly every day. Note: in
children, consider failure to
make expected weight gains.
Check if:

_____ weight loss or decreased
appetite
_____ weight gain or increased
appetite

? 1 2 3 A3

..how were you sleeping?
(Trouble falling asleep, waking
frequently, trouble staying
asleep, waking too early, OR
sleeping too much? How many
hours a night compared to usual?
Was that nearly every night?)

(4) insomnia or hypersomnia
nearly every day

Check if:

_____ insomnia

_____ hypersomnia

? 1 2 3 A6

..were you so fidgety or restless
that you were unable to sit still?
(Was it so bad that other people
noticed it? What did they notice?
Was that nearly every day?)

(5) psychomotor agitation or
retardation nearly every day
(observable by others, not
merely subjective feelings of
restlessness or being slowed
down)

? 1 2 3 A9

NOTE: CONSIDER
BEHAVIOR DURING
THE INTERVIEW

Check if:

_____ psychomotor retardation

_____ psychomotor agitation

A10

A11

IF NO: What about the
opposite -- talking or moving
more slowly than is normal
for you? (Was it so bad that
other people noticed it? What
did they notice? Was that
nearly every day?)

..what was your energy like?
(Tired all the time? Nearly every
day?)

(6) fatigue or loss of
energy nearly every day

? 1 2 3 A12

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

SCID (DSM-IV)

Current MDE (WHS 3/96)

Mood Episodes

A.3

During this time...

..how did you feel about yourself? (Worthless?) (Nearly every day?)

IF NO: What about feeling guilty about things you had done or not done? (Nearly every day?)

(7) feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick)

NOTE: CODE "1" OR "2" IF ONLY LOW SELF-ESTEEM check if:

_____worthless
_____inappropriate guilt

? 1 2 3 A13

A14
A15

..did you have trouble thinking or concentrating? (What kinds of things did it interfere with?) (Nearly every day?)

IF NO: Was it hard to make decisions about everyday things? (Nearly every day?)

(8) diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others)

check if:
_____diminished ability to think
_____indecisiveness

? 1 2 3 A16

A17
A18

..were things so bad that you were thinking a lot about death or that you would be better off dead? What about thinking of hurting yourself?

IF YES: Did you do anything to hurt yourself?

(9) recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide

? 1 2 3 A19

NOTE: CODE "1" FOR SELF-MUTILATION W/O SUICIDAL INTENT

Check if:

_____thoughts of own death
_____suicidal ideation
_____specific plan
_____suicide attempt

A20
A21
A22
A23

AT LEAST FIVE OF THE ABOVE SXs [A (1-9)] ARE CODED "3" AND AT LEAST ONE OF THESE IS ITEM (1) OR (2)

IF UNCLEAR, GO TO PAGE A.1

1
3 A24
GO TO
*PAST
MAJOR
DEPRES-
SIVE
EPI-
SODE*,
A.12

IF UNCLEAR: Has (depressive episode/OWN EQUIVALENT) made it hard for you to do your work, take care of things at home, or get along with other people?

B. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

? 1 2 3 A25

GO TO *PAST MAJOR DEPRESSIVE EPISODE* A.12

Just before this began, were you physically ill?

C. Not due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or to a general medical condition

? 1 3 A26

Just before this began, were you taking any medications?

IF YES: Any change in the amount you were taking?

Just before this began, were you drinking or taking any street drugs?

IF GENERAL MEDICAL CONDITION OR SUBSTANCE MAY BE ETIOLOGICALLY ASSOCIATED WITH DEPRESSION, GO TO *GMC/SUBSTANCE* A.43 AND RETURN HERE TO MAKE RATING OF "1" OR "3."

DUE TO SUBSTANCE USE OR GMC. GO TO *PAST MAJOR DEPRESSIVE EPISODE* A.12

Etiological general medical conditions include: degenerative neurological illnesses (e.g., Parkinson's disease, Huntington's disease, cerebrovascular disease, metabolic and endocrine conditions [e.g., B-12 deficiency, hypothyroidism], autoimmune conditions [e.g., systemic lupus erythematosus], viral or other infections [e.g., hepatitis, mononucleosis, HIV], and certain cancers [e.g., carcinoma of the pancreas]

Etiological substances include alcohol, amphetamines, cocaine, hallucinogens, inhalants, opioids, phencyclidine, sedatives, hypnotics, anxiolytics, and other or unknown substances (e.g., steroids)

PRIMARY MOOD EPISODE

CONTINUE BELOW

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

3 = threshold or true

***PAST MAJOR
DEPRESSIVE EPISODE*****MDE CRITERIA**

-> IF NOT CURRENTLY
DEPRESSED: Have you
ever had a period when you
were feeling depressed or
down most of the day nearly
every day? (What was that
like?)

-> IF CURRENTLY
DEPRESSED OR DOES
NOT MEET FULL
CRITERIA FOR PAST

MDE: Has there been
another time when you were
depressed or down most of
the day nearly every day?
(What was that like?)

IF YES: When was that? How
long did it last? (As long as two
weeks?)

-> IF PAST DEPRESSED
MOOD: During that time,
did you have little interest or
pleasure in doing things you
usually enjoyed? (What was
that like?)

-> IF NO PAST DEPRESSED
MOOD: What about a time
when you had little interest or
pleasure in doing things you
usually enjoyed? (What was
that like?)

IF YES: When was that? Was it
nearly every day? How long did
it last? (As long as two weeks?)

Have you had more than one
time like that? (Which time was
the worst?)

IF UNCLEAR: Have you had
any times like that in the past
year?

A. Five or more of the
following symptoms have been
present during the same two
week period and represent a
change from previous
functioning; at least one of the
symptoms was either (1)
depressed mood or (2) loss of
interest or pleasure.

(1) depressed mood most of
the day, nearly every day,
as indicated by either
subjective report (e.g., feels
sad or empty) or observation
made by others (e.g.,
appears tearful). Note: in
children and adolescents, can
be irritable mood.

2) markedly diminished
interest or pleasure in all, or
almost all, activities most of
the day, nearly every day (as
indicated either by subjective
account or observation made
by others)

?	1	2	3	A52
		\ /		
		/ \		
?	1	2	3	A53

IF
NEITHER
ITEM (1)
NOR (2) IS
CODED "3,"
GO TO
DYSTHYMIA,
A.38

NOTE: IF MORE THAN ONE
PAST EPISODE IS LIKELY,
SELECT THE "WORST" ONE
FOR YOUR INQUIRY ABOUT
A PAST MAJOR DEPRESSIVE
EPISODE. HOWEVER, IF
THERE WAS AN EPISODE IN
THE PAST YEAR, ASK
ABOUT THAT EPISODE
EVEN IF IT WAS NOT THE
WORST.

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

FOR THE FOLLOWING QUESTIONS, FOCUS ON THE WORST TWO WEEKS OF THE PAST MDE YOU ARE EVALUATING. DO NOT EVALUATE A CURRENT MDE.

During that (TWO WEEK PERIOD)...

NOTE: WHEN RATING THE FOLLOWING ITEMS, CODE "1" IF CLEARLY DIRECTLY DUE TO A GENERAL MEDICAL CONDITION, OR TO MOOD-INCONGRUENT DELUSIONS OR HALLUCINATIONS

..did you lose or gain any weight? (How much?) (Were you trying to lose weight?)

IF NO: How was your appetite? (What about compared to your usual appetite?) (Did you have to force yourself to eat?) (Eat [less/more] than usual?) (Was that nearly every day?)

(3) significant weight loss when not dieting, or weight gain (e.g., a change of more than 5% of body weight in a month) or decrease or increase in appetite nearly every day. Note: in children, consider failure to make expected weight gains. Check if:

_____ weight loss or decreased appetite

_____ weight gain or increased appetite

? 1 2 3 A54

A55

A56

..how were you sleeping? (Trouble falling asleep, waking frequently, trouble staying asleep, waking too early, OR sleeping too much? How many hours a night compared to usual? Was that nearly every night?)

(4) insomnia or hypersomnia nearly every day

Check if:

_____ insomnia

_____ hypersomnia

? 1 2 3 A57

A58

A59

..were you so fidgety or restless that you were unable to sit still? (Was it so bad that other people noticed it? What did they notice? Was that nearly every day?)

(5) psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down)

Check if:

_____ psychomotor retardation

_____ psychomotor agitation

? 1 2 3 A60

A61

A62

IF NO: What about the opposite -- talking or moving more slowly than is normal for you? (Was it so bad that other people noticed it? What did they notice? Was that nearly every day?)

..what was your energy like? (Tired all the time? Nearly every day?)

(6) fatigue or loss of energy nearly every day

? 1 2 3 A63

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

During this time...

..how did you feel about yourself?
(Worthless?) (Nearly every day?)

IF NO: What about
feeling guilty about
things you had done or
not done? (Nearly
every day?)

(7) feelings of worthlessness or
excessive or inappropriate guilt
(which may be delusional) nearly
every day (not merely self-reproach
or guilt about being sick)

NOTE: CODE "1" OR "2" IF
ONLY LOW SELF-ESTEEM
check if:

_____ worthless
_____ inappropriate guilt

? 1 2 3 A64

A65
A66

..did you have trouble thinking or
concentrating? (What kinds of
things did it interfere with?)
(Nearly every day?)

IF NO: Was it hard to
make decisions about
everyday things? (Nearly
every day?)

(8) diminished ability to think or
concentrate, or indecisiveness,
nearly every day (either by
subjective account or as observed
by others)

check if:

_____ diminished ability to think
_____ indecisiveness

? 1 2 3 A67

A68
A69

..were things so bad that you were
thinking a lot about death or that
you would be better off dead?
What about thinking of hurting
yourself?

IF YES: Did you do
anything to hurt yourself?

(9) recurrent thoughts of death
(not just fear of dying), recurrent
suicidal ideation without a specific
plan, or a suicide attempt or a
specific plan for committing suicide

NOTE: CODE "1" FOR SELF-
MUTILATION W/O SUICIDAL
INTENT

Check if:

_____ thoughts of own death
_____ suicidal ideation
_____ specific plan
_____ suicide attempt

? 1 2 3 A70

A71
A72
A73
A74

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

AT LEAST FIVE OF THE
ABOVE SXS [A(1-9)] ARE
CODED "3" AND AT LEAST
ONE OF THESE IS ITEM (1)
OR (2)

1

3

A75

IF NOT ALREADY ASKED:

Has there ever been any other
time when you were
(depressed/own equivalent) and
had even more of the symptoms
than I just asked you about?

-> IF YES: RETURN TO *PAST
MAJOR DEPRESSIVE
EPISODE* A.12 AND
CHECK WHETHER THERE
HAVE BEEN ANY OTHER
MAJOR DEPRESSIVE EPI-
ISODES THAT WERE MORE
SEVERE AND/OR CAUSED
MORE SYMPTOMS. IF SO,
ASK ABOUT THAT EPISODE.

-> IF NO: GO TO *CURRENT
DYSTHYMIA* A.38

IF UNCLEAR: Has (depressive
episode/own equivalent) made it
hard for you to do your work,
take care of things at home, or
get along with other people?

B. The symptoms cause
clinically significant distress or
impairment in social,
occupational, or other important
areas of functioning.

?

1

2

3...A76

CON- TINUE

IF NOT ALREADY ASKED:

Has there been any other time
when you were (depressed/
OWN EQUIVALENT) and it
caused you even more problems
than I just asked you about?

-> IF YES: RETURN TO *PAST
MAJOR DEPRESSIVE
EPISODE* A.12 AND
CHECK WHETHER THERE
HAVE BEEN ANY OTHER
MAJOR DEPRESSIVE
EPISODES THAT WERE
MORE SEVERE AND/OR
CAUSED MORE SYMPTOMS.
IF SO, ASK ABOUT THAT
EPISODE.

-> IF NOT: GO TO
CURRENT DYSTHYMIA
A.38

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

Just before this began, were you physically ill?

IF YES: What did the doctor say?

Just before this began, were you taking any medications?

IF YES: Any change in the amount you were taking? Did you begin a new medication?

Just before this began, were you drinking or taking any street drugs?

C. Not due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or to a general medical condition

?

1

3

A.77

DUE TO SUB-
STANCE USE
OR GMC

IF GENERAL MEDICAL
CONDITION OR SUBSTANCE
MAY BE ETIOLOGICALLY
ASSOCIATED WITH
DEPRESSION, GO TO
SUBSTANCE/GMC A.43.
AND RETURN HERE TO MAKE
RATING OF "1" OR "3."

REFER TO LIST OF GENERAL
MEDICAL CONDITIONS AND
SUBSTANCES, A.4.

IF UNKNOWN: Has there been any other time when you were depressed like this but were not using SUBSTANCE/ ill with GMC)?

PRIMARY
MOOD
EPISODE

CONTINUE

> IF YES; GO TO *PAST MAJOR DEPRESSIVE EPISODE* A.12 AND CHECK WHETHER THERE HAVE BEEN ANY OTHER MAJOR DEPRESSIVE EPISODES THAT WERE MORE SEVERE AND/OR CAUSED MORE SYMPTOMS. IF SO, ASK ABOUT THAT EPISODE.

> IF NO: GO TO *CURRENT DYSTHYMIA* A.38

SCID-I (DSM-IV) Version 2.0

(Did this begin soon after someone close to you died?)

Past MDE (WHS 3/96)

D. Not better accounted for by Bereavement, i.e., after the loss of a loved one, the symptoms persist for longer than 2 months or are characterized by marked functional impairment, morbid preoccupation with worthlessness, suicidal ideation, psychotic symptoms, or psychomotor retardation.

Mood Episodes

? 1

SIMPLE
BEREAVE-
MENT

A.17
A78

3

AT LEAST
ONE
MAJOR
EPISODE
NOT
SIMPLE
BEREAVE-
MENT

IF UNKNOWN: Has there been any other time when you were depressed like this that did not occur after someone close to you died?

-> IF YES: GO TO *PAST MAJOR DEPRESSIVE EPISODE* A12 AND CHECK WHETHER THERE HAVE BEEN ANY OTHER MAJOR DEPRESSIVE EPISODES THAT WERE MORE SEVERE AND/OR CAUSED MORE SYMPTOMS. IF SO, ASK ABOUT THAT EPISODE.

-> IF NO: GO TO *CURRENT DYSTHYMIA* A.38

CON-
TINUE

MAJOR DEPRESSIVE EPISODE
CRITERIA A, B, C and D are
coded "3"

1

GO TO
*CUR-
RENT
DYSTHY-
MIA*
A.38

3

A79

PAST
MAJOR
DEPRES-
SIVE
EPISODE

How old were you when (PAST MAJOR DEPRESSIVE EPISODE) started?

Age at onset of Past Major Depressive Episode (coded above)

A80

How many separate times have you been (depressed/OWN EQUIVALENT) nearly every day for at least two weeks and had several of the symptoms that you described, like (SXS OF WORST EPISODE)?

Total number of Major Depressive Episodes, including current (CODE 99 IF TOO NUMEROUS OR INDISTINCT TO COUNT)

A81

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

IF UNKNOWN: How old were
you when first started having
(SXS OF MDE)?

Age of onset of first Major
Depressive Episode (CODE 99 IF
UNKNOWN)

Mo./Yr.: ____/____ Age: ____

ESTABLISH WHETHER MDE
OR CANCER DX. CAME
FIRST. CODE THIS
INFORMATION ON SUMMARY
SCORE SHEET.

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

***DYSTHYMIC DISORDER*
(CURRENT ONLY)****DYSTHYMIC DISORDER CRITERIA**

-> IF NO MAJOR DEPRESSIVE EPISODE IN THE PAST TWO YEARS: For the past couple of years, have you been bothered by depressed mood most of the day, more days than not? (More than half the time?)

IF YES: What was that like?

-> IF CURRENT MAJOR DEPRESSIVE EPISODE: Let's review when you first had most of the symptoms of (CURRENT MAJOR DEPRESSIVE EPISODE). For the two years prior to (BEGINNING DATE), were you bothered by depressed moods, most of the day, more days than not? (More than half the time?)

-> FOR A PAST MAJOR DEPRESSIVE EPISODE DURING THE PAST TWO YEARS: Let's review when you first had most of the symptoms of (PAST MAJOR DEPRESSIVE EPISODE) and the point at which you no longer had most of the symptoms. Since the (DATE OF NO LONGER MEETING CRITERIA), have you still been bothered by depressed mood, so that you have been depressed for most of the day, more days than not?

IF YES: For the two years prior to (DATE OF BEGINNING OF PAST MAJOR DEPRESSIVE EPISODE), were you bothered by depressed mood, most of the day, more days than not? (More than half the time?)

A. Depressed mood (or can be irritable mood in children and adolescents) for most of the day, for more days than not, as indicated either by subjective account or observation made by others, for at least two years (one year for children and adolescents)

? 1 2 3 A163

GO TO
*ALCOHOL
USE
DISORDERS*
E.1

FIRST MET CRITERIA FOR
CURRENT MAJOR
DEPRESSIVE EPISODE
(see A.5):

Mo/Yr: ____ / ____ Age: ____

FIRST MET CRITERIA FOR
PAST MAJOR DEPRESSIVE
EPISODE (see A.17):

Mo/Yr: ____ / ____ Age: ____

NO LONGER MET CRITERIA
FOR PAST MAJOR
DEPRESSIVE EPISODE IN
PAST TWO YEARS:

Mo/Yr: ____ / ____ Age: ____

During these periods of (OWN EQUIVALENT FOR CHRONIC DEPRESSION), do you often...

B. Presence, while depressed, of two (or more) of the following:

...lose you appetite?(What about overeating?)	(1) poor appetite or overeating	?	1	2	3	A164
...have trouble sleeping or sleep too much	(2) insomnia or hypersomnia	?	1	2	3	A165
...have little energy to do things or feel tired a lot?	(3) low energy or fatigue	?	1	2	3	A166
...feel down on yourself? (Feel worthless, or a failure?)	(4) low self-esteem	?	1	2	3	A167
... have trouble concentrating or making decisions?	(5) poor concentration or difficulty making decisions	?	1	2	3	A168
...feel hopeless?	(6) feelings of hopelessness	?	1	2	3	A169
	AT LEAST TWO "B" SYMPTOMS CODED "3"	?	1	2	3	A170

GO TO
*ALCOHOL
USE DIS-
ORDERS*
E.1

What is the longest period of time, during this period of long-lasting depression, that you felt ok?(NO DYSTHYMIC SYMPTOMS)

C. During the two year period (one-year for children or adolescents) of the disturbance, the person has never been without the symptoms in A and B for more than two months at a time.

? 1 3 A171

GO TO
*ALCOHOL
USE DIS-
ORDERS*
E.1

NOTE: CODE "1" IF NORMAL MOOD FOR AT LEAST TWO MONTHS AT A TIME

How long have you been feeling this way? (When did this begin?)

COMPARE ONSET OF DYSTHYMIC SXS WITH DATES OF PAST MAJOR DEPRESSIVE EPISODES TO DETERMINE IF THERE WERE ANY MAJOR DEPRESSIVE EPISODES IN FIRST TWO YEARS OF DYSTHYMIC DISORDER.

D. No major depressive episode during the first two years of disturbance (one year for children and adolescents); i.e., not better accounted for by chronic Major Depressive Disorder in partial remission.

? 1 2 3 A172

GO TO
*ALCOHOL
USE DIS-
ORDERS*
E.1

Age at onset of current Dysthymic Disorder (CODE 99 IF UNKNOWN)

— —

A173

IF MAJOR DEPRESSIVE EPISODE PRECEDED DYSTHYMIC SXS: Now I want to know whether you got completely back to your usual self after that (MAJOR DEPRESSIVE EPISODE) you had (DATE), before this long period of being mildly depressed? (Were you back to your usual self for at least two months?)

Note: There may have been a previous Major Depressive Episode provided there was a full remission (no significant signs or symptoms for two months) before development of the Dysthymic Disorder. In addition, there may be superimposed episodes of Major Depressive Disorder, in which case both diagnoses may be given.

NOTE: CODE "3" IF NO PAST MAJOR DEPRESSIVE EPISODES OR IF MAJOR DEPRESSIVE EPISODES WERE NOT PRESENT DURING THE FIRST TWO YEARS OR IF THERE WAS AT LEAST A TWO MONTHS PERIOD WITHOUT SYMPTOMS PRECEDING THE ONSET.

E. Has never had a Manic Episode or an unequivocal Hypomanic Episode.

1 3

A174

GO TO
*ALCOHOL USE
DISORDERS* E.1

F. Does not occur exclusively during the course of a chronic psychotic disorder, such as Schizophrenia or Delusional Disorder.

? 1 3 A175

GO TO
*ALCO-
HOL USE
DISORDERS*
E.1

NOT
SUPER-
IMPOSED

CON-
TINUE

NOTE: CODE "3" IF NO CHRONIC PSYCHOTIC DISORDER OR IF NOT SUPERIMPOSED ON A CHRONIC PSYCHOTIC DISORDER.

Just before this began, were you physically ill?

IF YES: What did the doctor say?

Just before this began, were you taking any medications?

IF YES: Any change in the amount you were taking?
Did you begin a new medication?

Just before this began, were you drinking or using any street drugs?

G. Not due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or to a general medical condition

IF GENERAL MEDICAL CONDITION OR SUBSTANCE MAY BE ETIOLOGICALLY ASSOCIATED WITH DEPRESSION, GO TO *SUBSTANCE/GMC* A.43
RETURN HERE AND MAKE RATING OF "1" OR "3"

Etiological general medical conditions include: degenerative neurological illnesses (e.g., Parkinson's disease, Huntington's disease, cerebrovascular disease, metabolic and endocrine conditions (e.g., B-12 deficiency, hypothyroidism), autoimmune conditions (e.g., systemic lupus erythematosus), viral or other infections (e.g., hepatitis, mononucleosis, HIV), and certain cancers (e.g. carcinoma of the pancreas)

Etiological substances include: alcohol, amphetamines, cocaine, hallucinogens, inhalants, opioids, phencyclidine, sedatives, hypnotics, anxiolytics, and other known or unknown substances (e.g., steroids).

IF UNCLEAR: How much do your depressed feelings interfere with your life?

H. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

DYSTHYMIC DISORDER
CRITERIA A, B, C, D, E, F,
AND H ARE CODED "3"

IF DYSTHYMIC DISORDER
Indicate specifier:

- 1- Early Onset: onset before age 21
2- Late Onset: onset age 21 or older

? 1 3

DUE TO
SUBSTANCE
USE OR GMC

GO TO
*ALCOHOL
USE DIS-
ORDERS*
E.1

3

A176

PRIMARY
MOOD
DISORDER

CONTINUE

? 1 3

GO TO *ALCOHOL
USE DISORDERS*
E.1

3

A177

1

3

A178

GO TO
*ALCOHOL
USE DIS-
ORDERS*
E.1

DYS-
THYMIC
DIS-
ORDER

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

Specifier: _____

A179

GMC/SUBSTANCE CAUSING MOOD/ANXIETY SYMPTOMS

**MOOD/ANXIETY DISORDER
DUE TO A GENERAL
MEDICAL CONDITION**

**MOOD/ANXIETY DISORDER
DUE TO A GENERAL MEDICAL
CRITERIA**

IF SYMPTOMS NOT TEMPORALLY ASSOCIATED WITH A GENERAL MEDICAL CONDITION,
CHECK HERE _____ AND GO TO ***SUBSTANCE INDUCED MOOD DISORDER*, A45.**

A187

CODE BASED ON
INFORMATION ALREADY
OBTAINED.

A. Prominent and persistent
disturbance in mood/anxiety
characterized by the following:

(1) depressed mood or markedly
diminished interest or pleasure in
all, or almost all, activities [FOR
MOOD]

? 1 2 3

A188

(2) prominent anxiety, panic
attacks, obsession or compulsions
[FOR ANXIETY]

? 1 3

A189

Do you think your (MOOD/
ANXIETY SXS) were in any way
related to your (COMORBID
GENERAL MEDICAL
CONDITION)?

B./C. There is evidence from the
history, physical examination, or
laboratory findings that the
disturbance is the direct
physiological consequence of a
general medical condition and the
disturbance is not better accounted
for by another mental disorder
(e.g., Adjustment Disorder With
Depressed Mood, in response to
the stress of having a general
medical condition).

? 1 2 3

A190

GO TO
*SUB-
STANCE
INDUCED*
A.45

IF YES: Tell me how.

(Did the [MOOD/ANXIETY SXS]
start or get much worse only after
[COMORBID GENERAL
MEDICAL CONDITION] began?)

IF YES AND GMC HAS
RESOLVED:
Did the (MOOD/ANXIETY
SXS) get better once the
(COMORBID GENERAL
MEDICAL CONDITION)
got better?

THE FOLLOWING FACTORS
SHOULD BE CONSIDERED
AND SUPPORT THE CONCLU-
SION THAT THE GMC IS ETIO-
LOGIC TO THE
MOOD/ANXIETY SXS:

1) THERE IS EVIDENCE FROM
THE LITERATURE OF A WELL-
ESTABLISHED ASSOCIATION
BETWEEN THE GMC AND
MOOD/ANXIETY SYMPTOMS.

2) THERE IS A CLOSE
TEMPORAL RELATIONSHIP
BETWEEN THE COURSE OF
THE MOOD/ANXIETY SXS AND
THE COURSE OF THE
GENERAL MEDICAL CONDI-
TION.

3) THE MOOD/ANXIETY SYMPTOMS ARE CHARACTERIZED BY UNUSUAL PRESENTING FEATURES (E.G., LATE AGE AT ONSET)

4) THE ABSENCE OF ALTERNATIVE EXPLANATIONS (E.G., MOOD/ANXIETY SYMPTOMS AS A PSYCHOLOGICAL REACTION TO THE GMC)

IF UNCLEAR : How much did (MOOD/ANXIETY SYMPTOMS) interfere with your life?

E. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning

? 1 2 3 A191

GO TO
*SUB-
STANCE-
INDUCED*
A.45

D. The disturbance does not occur exclusively during the course of Delirium.

1 3 A192

DELIRIUM
DUE TO A
GMC

MOOD/
ANXIETY
DISORDER
DUE TO A
GMC

RETURN TO EPISODE
BEING EVALUATED

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

***SUBSTANCE -INDUCED
MOOD/ANXIETY
DISORDER***

IF SYMPTOMS NOT TEMPORAL-
LY ASSOCIATED WITH SUB-
STANCE, CHECK HERE _____
AND RETURN TO EPISODE BE-
ING EVALUATED.

CODE BASED ON
INFORMATION ALREADY
OBTAINED.

**SUBSTANCE-INDUCED
MOOD/ANXIETY
DISORDER CRITERIA****EPISODE BEING EVALUATED:**

Current MDE	A.1
Past MDE	A.12
Dysthymia	A.38
Current GAD	F.31
MAD	J.8

A. A prominent and persistent
disturbance in mood/anxiety
characterized by the following:

(1) depressed mood or markedly
diminished interest or pleasure in
all, or almost all, activities [FOR
MOOD].

? 1 2 3 A194

(2) prominent anxiety, panic
attacks, obsession or compulsions
[FOR ANXIETY]

? 1 2 3 A195

IF NOT KNOWN: When did the
(MOOD/ANXIETY SYMPTOMS)
BEGIN? (Were you already
(SUBSTANCE) or had you just
stopped or cut your use?

B. There is evidence from the
history, physical examination, or
laboratory findings that either
(1) the symptoms in A developed
during or within a month of
substance Intoxication or
withdrawal, or (2) medication use
is etiologically related to the
disturbance.

? 1 2 3 A196

NOT SUBSTANCE
INDUCED RETURN
TO EPISODE BEING
EVALUATED

Do you think your (MOOD/
ANXIETY SXS) are in any way
related to your (SUBSTANCE
USE)?

C. The disturbance is not better
accounted for by a Mood/Anxiety
Disorder that is not substance-
induced. Evidence that the
symptoms are better accounted for
by a Mood Disorder that is not
substance-induced might include:

? 1 2 3 A197

NOT SUBSTANCE
INDUCED RETURN
TO EPISODE BEING
EVALUATED

IF YES: Tell me how.

ASK ANY OF THE
FOLLOWING QUESTIONS AS
NEEDED TO RULE OUT A
NON-SUBSTANCE-INDUCED
ETIOLOGY:

IF UNKNOWN: Which came first,
the (SUBSTANCE USE) or the
(MOOD/ANXIETY SYMPTOMS)?

1) the mood/anxiety symptoms
precede the onset of the Substance
Abuse or Dependence

IF UNKNOWN: Have you had a
period of time when you stopped
using (SUBSTANCE)?

2) the mood/anxiety symptoms
persist for a substantial period of
time (e.g., about a month after the
cessation of acute withdrawal or
severe intoxication)

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

IF YES: After you stopped using (SUBSTANCE) did the (MOOD/ANXIETY SYMPTOMS) get better?

IF UNKNOWN: How much of (SUBSTANCE) were you taking when you began to have (MOOD/ANXIETY SYMPTOMS)?

IF UNKNOWN: Have you had any other episodes of (MOOD/ANXIETY SYMPTOMS)?

IF YES: How many? Were you taking (SUBSTANCES) at those times?

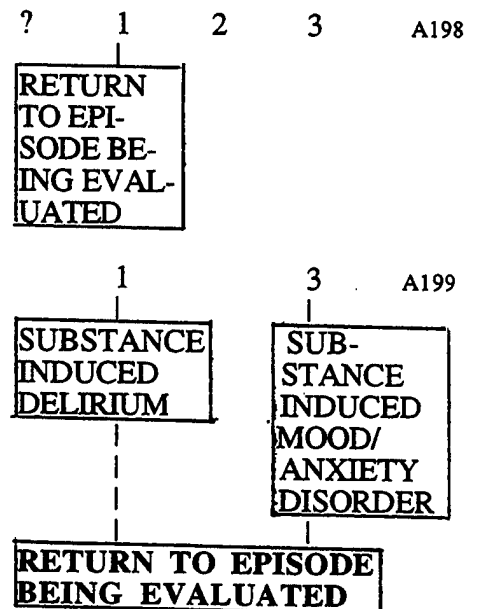
IF UNKNOWN: How much did (MOOD/ANXIETY SYMPTOMS) interfere with your life?

3) the mood symptoms are substantially in excess of what would be expected given the character, duration, or amount of the substance used

4) There is evidence suggesting the existence of an independent non-substance-induced Mood/Anxiety Disorder (e.g., a history of recurrent non-substance-related Major Depressive Episodes).

E. The symptoms cause clinically significant distress or impairment in social, occupational, or their important areas of functioning.

D. The disturbance does not occur exclusively during the course of Delirium.



E. SUBSTANCE USE DISORDERS

ALCOHOL USE DISORDERS (LIFETIME)

IF QUESTIONS J3, J4, J5, AND J6 FROM WHS QUESTIONNAIRE ANSWERED "NO," CHECK HERE _____ AND SKIP TO ***GENERAL ANXIETY DISORDER*, F.31.**

IF SCREENERS NOT USED OR IF ANY OF J3, J4, J5, OR J6 FROM WHS QUESTIONNAIRE ANSWERED "YES," CONTINUE:

What are your drinking habits like?
(How much do you drink?)

When in your life were you drinking
the most? (How long did that period
last?)

During that time...

how often were you drinking?

RECORD DATE OF HEAVIEST
USE AND DESCRIBE PATTERN:

what were you drinking? how
much?

During that time...

did your drinking cause problems
for you?

did anyone object to your drinking?

IF ALCOHOL DEPENDENCE SEEMS
LIKELY, CHECK HERE _____ AND
SKIP TO ***ALCOHOL DEPENDENCE*,
E.4.**

E1

OTHERWISE, CONTINUE WITH
ALCOHOL ABUSE
ON NEXT PAGE.

LIFETIME ALCOHOL ABUSE

Let me ask you a few more questions about your drinking habits.

Have you ever been intoxicated or high or very hung over while you were doing something important, like being at school or work, or taking care of children?

IF NO: What about missing something important, like staying away from school or work or missing an appointment because you were intoxicated, high, or very hung over?

IF YES TO EITHER OF ABOVE:
How often? (Over what period of time?)

Did you ever drink in a situation in which it might have been dangerous to drink at all? (Did you ever drive while you were really too drunk to drive?)

IF YES AND UNKNOWN: How often? (Over what period of time?)

Has your drinking gotten you into trouble with the law?

IF YES AND UNKNOWN: How often? (Over what period of time?)

IF NOT ALREADY KNOWN: Has your drinking caused you problems with other people, such as family members, friends, or people at work? (Have you ever gotten into physical fights or had bad arguments about your drinking?)

IF YES: Did you keep on drinking anyway? (Over what period of time?)

ALCOHOL ABUSE CRITERIA

A. A maladaptive pattern of substance use leading to clinically significant impairment or distress, as manifested by one (or more) of the following occurring within a twelve month period:

(1) recurrent alcohol use resulting in a failure to fulfill major role obligations at work, school, or home (e.g., repeated absences or poor work performance related to alcohol use; alcohol-related absences, suspensions, or expulsions from school; neglect of children or household)	?	1	2	3	E2
(2) recurrent alcohol use in situations in which it is physically hazardous (e.g., driving an automobile or operating a machine when impaired by alcohol use)	?	1	2	3	E3
(3) recurrent alcohol-related legal problems (e.g., arrests for alcohol-related disorderly conduct)	?	1	2	3	E4
(4) continued alcohol use despite having persistent or recurrent social or interpersonal problems caused or exacerbated by the effects of alcohol (e.g., bad arguments with spouse about consequences of intoxication, physical fights)	?	1	2	3	E5

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

AT LEAST ONE "A" ITEM
CODED "3"

? 1

3

E6

IF NO POSSIBILITY OF PHYSIOLOGICAL DEPENDENCE OR
COMPULSIVE USE, GO TO ***GENERALIZED ANXIETY
DISORDER,* F.31.** OTHERWISE, CONTINUE ASKING ABOUT
DEPENDENCE, E.4.

ALCOHOL
ABUSE.
CONTINUE
ASKING
ABOUT
DEPEND-
ENCE
E.4

ALCOHOL DEPENDENCE

I'd now like to ask you some more questions about your drinking habits.

ALCOHOL DEPENDENCE CRITERIA

A maladaptive pattern of alcohol use, leading to clinically significant impairment or distress, as manifested by three (or more) of the following occurring at any time in the same twelve month period:

NOTE: CRITERIA FOR ALCOHOL DEPENDENCE ARE NOT IN DSM IV ORDER

Have you often found that when you started drinking you ended up drinking more than you were planning to?

(3) alcohol is often taken in larger amounts OR over a longer period than was intended

? 1 2 3 E7

IF NO: What about drinking for a much longer period of time than you were planning to?

Have you tried to cut down or stop drinking alcohol?

(4) there is a persistent desire OR unsuccessful efforts to cut down or control substance use

? 1 2 3 E8

IF YES: Did you ever actually stop drinking altogether?

(How many times did you try to cut down or stop altogether?)

IF NO: Did you want to stop or cut down? (Is this something you kept worrying about?)

Have you spent a lot of time drinking, being high, or hung over?

(5) a great deal of time is spent in activities necessary to obtain alcohol, use alcohol, or recover from its effects

? 1 2 3 E9

Have you had times when you would drink so often that you started to drink instead of working or spending time at hobbies or with your family or friends?

(6) important social, occupational, or recreational activities given up or reduced because of alcohol use

? 1 2 3 E10

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

IF NOT ALREADY KNOWN: Has your drinking ever caused any psychological problems like making you depressed or anxious, making it difficult to sleep, or causing "blackouts?"

IF NOT ALREADY KNOWN: Has your drinking ever caused significant physical problems or made a physical problem worse?

IF YES TO EITHER OF THE ABOVE: Did you keep on drinking anyway?

Have you found that you needed to drink a lot more in order to get the feeling you wanted than you did when you first started drinking?

IF YES: How much more?

IF NO: What about finding that when you drank the same amount, it had much less effect than before?

Have you ever had any withdrawal symptoms when you cut down or stopped drinking like...

...sweating or racing heart?

...hand shakes?

...trouble sleeping?

...feeling nauseated or vomiting?

...feeling agitated?

...or feeling anxious?

(How about having a seizure or seeing, feeling, or hearing things that weren't really there?)

IF NO: Have you ever started the day with a drink, or did you often drink to keep yourself from getting the shakes or becoming sick?

(7) alcohol use is continued despite knowledge of having a persistent or recurrent physical problem that is likely to have been caused or exacerbated by alcohol (e.g., continued drinking despite recognition that an ulcer was made worse by alcohol consumption)

(1) tolerance, as defined by either of the following:

(a) a need for markedly increased amounts of alcohol to achieve intoxication or desired effect

(b) markedly diminished effect with continued use of the same amount of alcohol

(2) withdrawal, as manifested by either (a) or (b):

(a) at least TWO of the following:

-- autonomic hyperactivity (e.g., sweating or pulse rate greater than 100)
-- increased hand tremor
-- insomnia
-- nausea or vomiting
-- psychomotor agitation
-- anxiety

-- grand mal seizures
-- transient visual, tactile, or auditory hallucination or illusions

(b) alcohol (or a substance from the sedative/hypnotic/anxiolytic class) taken to relieve or avoid withdrawal symptoms

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

E11

E12

E13

E14

IF UNKNOWN: When did (SXS CODED "3" ABOVE) occur? (Did they all happen around the same time?)

AT LEAST THREE "A" ITEMS CODED "3" AND ITEMS OCCURRED WITHIN THE SAME TWELVE (12) MONTH PERIOD

1

3

E15

ALCOHOL
DEPENDENCE

Indicate if:

1 - With Physiological Dependence
(current evidence of tolerance or withdrawal)
2 - Without Physiological Dependence
(no current evidence of tolerance or withdrawal)

E16

GO TO DEPENDENCE CHRONOLOGY, E.7

IF ALCOHOL ABUSE QUESTIONS (PAGES E.1-E.3) HAVE NOT YET BEEN ASKED, GO TO PAGE E.1 AND CHECK FOR ABUSE.

IF ABUSE QUESTIONS HAVE BEEN ASKED AND ABUSE IS PRESENT, CODE "3"; OTHERWISE, IF QUESTIONS HAVE BEEN ASKED AND ABUSE IS NOT PRESENT, GO TO *GENERALIZED ANXIETY DISORDER F.31.

1

3

E17

GO TO
*GENER-
ALIZED
ANXIETY
DISOR-
DER* F.31

ALCO-
HOL
ABUSE

How old were you when you first had (ABUSE SXS CODED "3")?

Age at onset of Alcohol Abuse
(CODE 99 IF UNKNOWN)

— — —

E18

IF UNCLEAR: During the past month, have you had anything at all to drink?

Criteria for Alcohol Abuse met at any time in past month

1

3

E19

IF YES: Tell me more about it.
(Has your drinking caused you any problems?)

PAST
ABUSE

CUR-
RENT
ABUSE

GO TO
*GENERALIZED
ANXIETY
DISORDER,*
F.31

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

CHRONOLOGY FOR DEPENDENCE

How old were you when you first had
(LIST OF ALCOHOL DEPENDENCE
OR ABUSE SXS CODED "3")?

Age at onset of Alcohol
Dependence or Abuse (CODE 99
IF UNKNOWN)

— —

E20

IF UNCLEAR: During the past month,
have you had anything at all to drink?

Full criteria for Alcohol
Dependence met at any time in past
month (or never had a month
without symptoms of Dependence
or Abuse since onset of
Dependence)

1

3

E21

IF YES: Tell me more about it.
(Has your drinking caused you any
problems?)

CUR-
RENT
DE-
PEND-
ENCE

SEVERITY SPECIFIERS FOR DEPENDENCE

NOTE SEVERITY OF DEPENDENCE FOR WORST WEEK OF PAST MONTH
(Additional questions about the effect of alcohol on social and occupational functioning
may be necessary.)

E22

- 1-Mild: Few, if any, symptoms in excess of those required to make the diagnosis, and the symptoms result in no more than mild impairment in occupational functioning or in usual social activities or relationships with others (or criteria met for Dependence in the past and some current problems).
- 2-Moderate: Symptoms or functional impairment between "mild" and "severe."
- 3-Severe: Many symptoms in excess of those required to make the diagnosis, and the symptoms markedly interfere with occupational functioning or with usual social activities or relationships with others.

GO TO ***GENERALIZED ANXIETY DISORDER, F.31***

***GENERALIZED ANXIETY
DISORDER*
(CURRENT ONLY)**

**GENERALIZED ANXIETY
DISORDER CRITERIA**

In the past six months, was there a period when you were particularly nervous or anxious?

Do you also worry a lot about bad things that might happen?

IF YES: What do you worry about? (How much do you worry about [EVENTS OR ACTIVITIES])

During the last six months, would you say that you have been worrying (more days than not?)

When you're worrying this way, do you find that you can't stop yourself?

When did this anxiety start?
COMPARE ANSWER WITH
ONSET OF MOOD OR
PSYCHOTIC DISORDER.

A. Excessive anxiety and worry (apprehensive expectation), occurring more days than not for at least six months, about a number of events or activities (such as work or school performance)

B. The person finds it difficult to control the worry

F(2). Does not occur exclusively during the course of a Mood Disorder, Psychotic Disorder, or a Pervasive Developmental Disorder

? 1 2 3 F135

GO TO
*MIXED
ANXIETY
DISOR-
DER,* J.5

? 1 2 3 F136

GO TO
*MIXED
ANXIETY
DISOR-
DER,* J.5

? 1 2 3 F137

GO TO
*MIXED
ANXIETY
DISOR-
DER,* J.5

Now I am going to ask you some questions about other symptoms that often go along with being nervous.

C. The anxiety and worry are associated with at least three of the following such symptoms (with at least some symptoms present for more days than not for the past six months) :

Thinking about those periods in the past six months when you're feeling nervous or anxious...

...do you often feel physically restless -- can't sit still?

(1) restlessness or feeling keyed up or on edge

? 1 2 3 F138

...do you often feel keyed up or on edge?

...do you often tire easily?

(2) being easily fatigued

? 1 2 3 F139

...do you have trouble concentrating or does your mind go blank?

(3) difficulty concentrating or mind going blank

? 1 2 3 F140

... are you often irritable?

(4) irritability

? 1 2 3 F141

...are your muscles often tense?

(5) muscle tension

? 1 2 3 F142

...do you often have trouble falling or staying asleep?

(6) sleep disturbance (difficulty falling or staying asleep, or restless unsatisfying sleep)

? 1 2 3 F143

AT LEAST THREE "C" SXS ARE CODED "3"

1

3 F144

GO TO
*MIXED
ANXIETY
DISOR-
DER,* J.5

CODE BASED ON PREVIOUS INFORMATION.

D. The focus of the anxiety and worry is not confined to the features of another Axis I Disorder, e.g. being embarrassed in public (as in Social Phobia), being contaminated (as in Obsessive-Compulsive Disorder), being away from home or close relatives (as in Separation Anxiety Disorder), gaining weight (as in Anorexia Nervosa), or having a serious illness (as in Hypochondriasis), and is not part of Posttraumatic Stress Disorder.

? 1

3

F145

GO TO
*MIXED
ANXIETY
DISOR-
DER.* J.5

IF UNCLEAR: What effect has the anxiety, worry, or (PHYSICAL SYMPTOMS) had on your life? (Has it made it hard for you to do your work or be with your friends?)

E. The anxiety, worry, or physical symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning

? 1 2

3

F146

GO TO
*MIXED
ANXIETY
DISOR-
DER.* J.5

Just before you began having this anxiety, were you taking any drugs, stimulants or medicines?

(How much coffee, tea, or cola do you drink a day?)

Just before these problems began, were you physically ill?

IF YES: What did the doctor say?

F. Not due to the direct psychological effects of a substance (e.g., a drug of abuse, medication) or to a general medical condition

IF A GENERAL MEDICAL CONDITION OR SUBSTANCE MAY BE ETIOLOGICALLY ASSOCIATED WITH THE ANXIETY, GO TO *SUBSTANCE /GMC*, A.43 RETURN HERE TO MAKE RATING OF "1" OR "3".

Etiological general medical conditions include: hyper- and hypo-thyroidism, hypoglycemia, hyperparathyroidism, pheochromocytoma, congestive heart failure, arrhythmias, pulmonary embolism, chronic obstructive pulmonary disease, B-12 deficiency, porphyria, CNS neoplasms, vestibular dysfunction, encephalitis.

Etiological substances include: intoxicants with central nervous stimulants (e.g., cocaine, amphetamines, caffeine) or cannabis, hallucinogens, PCP, or alcohol, or withdrawal from central nervous system depressants (e.g., alcohol, sedatives, hypnotics) or cocaine

GENERALIZED ANXIETY CRITERIA A,B,C,D,E,AND F ARE CODED "3"

? 1
DUE TO SUBSTANCE USE OR A GMC

GO TO *MIXED ANXIETY DISORDER,* J.5

3 F147

PRIMARY ANXIETY DISORDER

CONTINUE

1
GO TO *MIXED ANXIETY DISORDER,* J.5

3 F148
GENERALIZED ANXIETY DISORDER

CHRONOLOGY OF GENERALIZED ANXIETY DISORDER

INDICATE CURRENT SEVERITY:

- 1-- **Mild:** Few, if any, symptoms in excess of those required to make the diagnosis are present, and symptoms result in no more than minor impairments in social or occupational functioning.
- 2-- **Moderate:** Symptoms or functional impairment between "mild" and "severe" are present.
- 3-- **Severe:** Many symptoms in excess of those required to make the diagnosis, or several symptoms that are particularly severe, are present, or the symptoms result in marked impairment in social or occupational functioning.

AGE AT ONSET

IF UNKNOWN: How old were
you when you first started having
(SXS OF GAD)?

Age at onset of Generalized
Anxiety Disorder (CODE 99 IF
UNKNOWN)

F149

GO TO ***MIXED ANXIETY
DISORDER* J.5.**

MAD**MIXED ANXIETY DISORDER CRITERIA
(APPENDIX CATEGORY)**

IF: CRITERIA HAVE EVER BEEN MET FOR MAJOR DEPRESSIVE DISORDER, DYSTHYMIC DISORDER, PANIC DISORDER, OR GENERALIZED ANXIETY DISORDER, CHECK HERE ____ AND END SCID INTERVIEW.

IF: CRITERIA ARE CURRENTLY MET FOR ANY OTHER ANXIETY OR MOOD DISORDER (INCLUDING AN ANXIETY DISORDER OR MOOD DISORDER IN PARTIAL REMISSION), CHECK HERE ____ AND END SCID INTERVIEW.

During the past month, have you been feeling bad...that is depressed or anxious for most of the time?

A. Persistent or recurrent dysphoric mood lasting at least one month.

? 1 2 3 J20

1
|
DONE

During those times when you're feeling bad...

B. The dysphoric mood is accompanied by at least 1 month of four (or more) of the following symptoms:

NOTE: FOR EACH OF THE FOLLOWING, MAKE SURE THE SYMPTOM LASTED AT LEAST 1 MONTH

...have you had trouble concentrating or does your mind go blank?

(1) difficulty concentrating or mind going blank

? 1 2 3 J21

...have you had trouble sleeping?

(2) sleep disturbance (difficulty falling or staying asleep, or restless unsatisfying sleep)

? 1 2 3 J22

...have you felt like you were tired all the time or that your energy was low?

(3) fatigue or low energy

? 1 2 3 J23

...have you felt irritable or cranky?

(4) irritability

? 1 2 3 J24

...did you worry a lot about things?

(5) worry

? 1 2 3 J25

...did you find yourself crying over little things?

(6) easily moved to tears

? 1 2 3 J26

...have you been watchful or on guard even when there is no reason to be?

(7) hypervigilance

? 1 2 3 J27

? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true

...when looking ahead, were you
expecting the worst?

(8) anticipating the worst

? 1 2 3 J28

...did you feel hopeless about the future?

(9) hopeless (pervasive pessimism
about the future)

? 1 2 3 J29

...did you feel down on yourself or that
you were worthless?

(10) low self-esteem or feelings of
worthlessness

? 1 2 3 J30

AT LEAST FOUR "B"
SYMPTOMS CODED "3"

? 1 3 J31

DONE

IF UNCLEAR: How much did these bad
feelings interfere with your life?

C. The symptoms cause clinically
significant distress or impairment
in social, occupational, or other
important areas of functioning.

? 1 2 3 J32

DONE

Just before you began having these symptoms, were you taking any drugs, stimulants or medicines?

(How much coffee, tea, or cola do you drink a day?)

Just before these problems began, were you physically ill? (What did the doctor say?)

D. Not due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or to a general medical condition

? 1 3 J33

DUE TO
SUBSTANCE
USE OR A
GMC.
DONE.

PRIMARY
ANXIETY
DISORDER

IF A GENERAL MEDICAL
CONDITION OR SUBSTANCE
MAY BE ETIOLOGICALLY
ASSOCIATED WITH THE
ANXIETY, GO TO
GMC/SUBSTANCE, A.43
AND RETURN HERE TO MAKE
RATING OF "1" OR "3."

Etiological general medical conditions include: hyper- and hypo-thyroidism, hypoglycemia, hyper-parathyroidism, pheochromocytoma, congestive heart failure, arrhythmias, pulmonary disease, pneumonia, hyperventilation, B-12 deficiency, porphyria, CNS neoplasms, vestibular dysfunction, encephalitis.

Etiological substance include: intoxication with central nervous stimulants (e.g., cocaine, amphetamines, caffeine) or cannabis, hallucinogens, PCP, or alcohol, or withdrawal from central nervous system depressants (e.g., alcohol, sedatives, hypnotics) or from cocaine.

CONTI-
NUE

E. All of the following:

? 1 3 J34

DONE

(1) Has never met criteria for Major Depressive Disorder, Dysthymic disorder, Panic Disorder, or Generalized Anxiety Disorder.

(2) Does not currently meet criteria for any other Anxiety or Mood Disorder (including an Anxiety or Mood Disorder in partial remission)

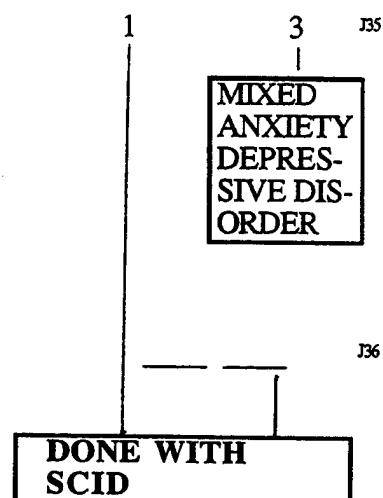
(3) Not better accounted for by any other mental disorder

CRITERIA A, B, C, D, AND E
ARE CODED "3"

AGE AT ONSET

IF UNKNOWN: How old were
you when you first started having
(SXS OF MAD)?

Age at onset of Mixed Anxiety
Depressive Disorder (CODE 99 IF
UNKNOWN)



? = inadequate information

1 = absent or false

2 = subthreshold

3 = threshold or true



UNIVERSITY OF
PENNSYLVANIA
MEDICAL CENTER



University of Michigan
Medical Center

WOMEN'S HEALTH STUDY

Interim Questionnaire

As you may already know, there are two components to this breast cancer research--a study of the biology of genetics, which is now located at the University of Pennsylvania (previously it was at the University of Michigan) and a study of the personal and social aspects of genetic testing which is located at the University of Michigan. This questionnaire is part of the study of personal and social aspects. Some of these questions will be familiar. We are asking them again to learn more about how feelings and attitudes change over time.

If you have any questions about this questionnaire or research, please feel free to call me at 313-998-6560. For questions about the genetic testing component, you may call Kathleen Calzone at the University of Pennsylvania, 215-349-8141. Thank you very much for your valuable participation in this research.

Sean Bouvrette
Project Manager
Women's Health Study
University of Michigan

TODAY'S DATE _____

ID _____

INTERIM QUESTIONNAIRE - A

GENETIC TESTING-SECTION 1

1. Have you contributed a blood or tissue sample to the GENETIC TESTING portion of the research project?

☐ Yes ☐ No

B21.

2. Has any member of your family contributed a blood or tissue sample to the GENETIC TESTING portion of the research project?

☐ Yes ☐ No ☐ I Don't Know

B22.

3. Have you or any family members received notification that genetic results are available? **B23.**

There Has Been No Notification	Results Are Available	Results Are NOT YET Available	Results will NEVER BE Available, I am Not Eligible

4. Have **you** received results of genetic testing for breast or ovarian cancer?

☐ Yes ☐ No (Skip to Question 5)

4a. When did this occur? _____(mo/yr)

4b. What was the source of this information?

☐ University of Pennsylvania ☐ Independent Testing ☐ Other: _____

4c. What were the results? (Optional)

5. Has **any family member** received results of genetic testing for breast or ovarian cancer?

☐ Yes ☐ No (Skip to Next Section) ☐ Don't Know (Skip to Next Section)

5a. When did this occur? _____(mo/yr)

5b. What was the source of this information?

☐ University of Pennsylvania ☐ Independent Testing ☐ Other: _____

5c. What were the results? (Optional)

- 5d. Can you infer your genetic results from your relative's results (i.e., Have you been able to figure out whether you are positive or negative for the gene that conveys higher risk for breast cancer with this information?)

☐ Yes ☐ No ☐ Don't Know

PERSONAL ATTITUDES SECTION

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	There is nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
j.	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
l.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
o.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

GENETIC TESTING-SECTION 2

1. A medical test may soon be available that allows some women to learn their genetic risk for developing a form of breast and ovarian cancer that runs in families. Even though you have been diagnosed with breast cancer, would you consider taking the genetic test to learn if your cancer is the type that runs in families?

(Please check one response).

B15.

- (1)._____ I will definitely take the test immediately when it becomes available.
 (2)._____ I will definitely take the test, but I am not sure if immediately.
 (3)._____ I will probably take the test immediately when it becomes available.
 (4)._____ I will probably take the test, but not immediately.
 (5)._____ I am undecided whether I will take the test
 (6)._____ I will probably not take the test.
 (7)._____ I will definitely not take the test.

2. On the following scale, indicate how distressing it is for you to know that you may be at increased risk for breast cancer because of your family history?

B66.

Not At All Distressing				Very Distressing
1	2	3	4	5

3. How distressing it is to be given the opportunity to be tested for the BRCA-1 gene, the altered gene associated with increased risk for breast cancer?

B67.

Not At All Distressing				Very Distressing
1	2	3	4	5

4. How distressed do you expect to be when you actually get tested for the BRCA-1 gene (before you receive results)?

B68.

Not At All Distressed				Very Distressed
1	2	3	4	5

5. How distressed would you be if you took the test and found that you **had** the BRCA-1 gene?

B69.

Not At All Distressed				Very Distressed
1	2	3	4	5

6. How distressed would you be if you took the test and found that you **did not have** the BRCA-1 gene? **B70.**

Not At All Distressed				Very Distressed
1	2	3	4	5

7. Overall, to what extent do you welcome the opportunity to be tested for the BRCA-1 gene? **B71.**

Not At All					Very Much So
1	2	3	4	5	

		Not At All					All The Time
8.	How often do you worry about again developing breast cancer?	1	2	3	4	5	B27.
9.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B28.
10.	How often do you worry about having the altered gene carrying risk for breast cancer ?	1	2	3	4	5	B29.
11.	To what extent do these worries you have about having this altered gene interfere with your every day life?	1	2	3	4	5	B30.

12. Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to other women? **(Please circle one)** **B7.**

Much Less Likely			Much More Likely	
1	2	3	4	5

13. When was the last time you had a mammography? **B32.**

_____Month _____Year (-8) ☐ This question does not apply because of surgery.

14. How many times have you conducted a breast self-examinations (BSE) in the past six months? **B33.**

_____times (-8) ☐ This question does not apply because of surgery.

15. How confident are you that you will perform breast self examination (BSE) ---

15a. --as **frequently** as needed? (-8) ☐ Does Not Apply Because of Surgery

B34a.

Not at All Very Much So
1 2 3 4 5 6 7

15b. --as **carefully and competently** as needed?

B34b.

(-8) ☐ Does Not Apply Because of Surgery

Not at All Very Much So
1 2 3 4 5 6 7

For each of the following areas of your life, you will asked to make **two** ratings. First, indicate how much these decisions have been affected by the possibility that you have an increased risk for breast cancer (based on your family history). Second, how much would these decisions be affected by the results of genetic testing ?

1	2	3	4	5
Not at all affected				Very much affected

		<u>Have been affected by being at risk for breast cancer</u>					<u>Would be affected by the results of genetic testing</u>					
16.	Decisions about having children	1	2	3	4	5	1	2	3	4	5	B34a.
17.	Decisions about form of birth control	1	2	3	4	5	1	2	3	4	5	B34b.
18.	Decisions about which steps to take to prevent the recurrence of breast cancer	1	2	3	4	5	1	2	3	4	5	B34c.
19.	Decisions about work and career	1	2	3	4	5	1	2	3	4	5	B34d.
20.	Decisions about savings and financial planning	1	2	3	4	5	1	2	3	4	5	B34e.
21.	Decisions about plans for the future	1	2	3	4	5	1	2	3	4	5	B34f.

22. Answer the following question only if you have daughters.

☐ Does Not Apply
(Skip to Next Section, Life Events)

B41.

		<u>Have been affected by being at high risk for breast cancer</u>					<u>Would be affected by the results of genetic testing</u>					
		1	2	3	4	5	1	2	3	4	5	
a.	Plans for your daughter's future											B42: B42I

LIFE EVENTS SECTION

1. Have any of the following events happened to you in the past six months?
(Check All That Apply)

D1(a-m)

- | | |
|--|---|
| a. <input type="checkbox"/> You retired, were fired, or laid off from work. | g. <input type="checkbox"/> A close family member was seriously ill or injured. |
| b. <input type="checkbox"/> You were unemployed and looking for work. | h. <input type="checkbox"/> You had a marital separation or divorce. |
| c. <input type="checkbox"/> Your spouse retired, was fired, or laid off from work. | i. <input type="checkbox"/> You had serious troubles with relatives or close friends. |
| d. <input type="checkbox"/> Your spouse was unemployed and looking for work. | j. <input type="checkbox"/> Your spouse had troubles or difficulties with relatives or close friends. |
| e. <input type="checkbox"/> You had problems with the police or court. | k. <input type="checkbox"/> A close family member died. |
| f. <input type="checkbox"/> You got into serious financial difficulties. | l. <input type="checkbox"/> A close friend or relative died. |
| | m. <input type="checkbox"/> You were seriously ill or injured. |

MARRIAGE SECTION

The following questions apply to persons who are married or living with a partner. If you are not married or living with a partner, check the appropriate box and please skip to the Next Section, MOOD.

Not married or living with a partner ☐

Ha.

Most persons have disagreements in their relationships. Please check the appropriate box to indicate the extent of agreement or disagreement experienced between you and your partner **DURING THE PAST MONTH**, regarding.

		<i>Always Agree</i>	<i>Almost Always Agree</i>	<i>Occasionally Disagree</i>	<i>Frequently Disagree</i>	<i>Almost Always Disagree</i>	<i>Always Disagree</i>	
1.	Religious matters	6	5	4	3	2	1	H3.
2.	Demonstration of affection	6	5	4	3	2	1	H4.
3.	Sex relations	6	5	4	3	2	1	H6.
4.	Conventionality (correct or proper behavior)	6	5	4	3	2	1	H7.
5.	Making major decisions	6	5	4	3	2	1	H12.
6.	Career decisions	6	5	4	3	2	1	H15.

		<i>All of the time</i>	<i>Most of the time</i>	<i>More often than most</i>	<i>Occasionally</i>	<i>Rarely</i>	<i>Never</i>	
7.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6	H16.
8.	Do you ever regret that you married (or are living together)?	1	2	3	4	5	6	H20.
9.	How often do you and your husband/partner quarrel?	1	2	3	4	5	6	H21.
10.	How often do you and your husband/partner "get on each other's nerves?"	1	2	3	4	5	6	H22.

		<i>All of Them</i>	<i>Most of Them</i>	<i>Some of Them</i>	<i>Very few of Them</i>	<i>None of Them</i>
11.	Do you and your husband/partner engage in outside interests together?	5	4	3	2	1

H24.

How often would you say the following events occur between you and your husband/partner?

		<i>Never</i>	<i>Less than once a month</i>	<i>About twice a month</i>	<i>About twice a week</i>	<i>Once a day</i>	<i>More Often</i>
12.	Have a stimulating exchange of ideas	1	2	3	4	5	6
13.	Calmly discuss something	1	2	3	4	5	6
14.	Work together on a project	1	2	3	4	5	6

H25.

H27.

H28.

15. Considering **only the positive feelings** you have toward your husband/partner, and **ignoring the negative ones**, please rate how positive these feelings are:

H33.

Not At All Positive									Extremely Positive
1	2	3	4	5	6	7	8	9	10

16. Considering **only the negative feelings** you have toward your husband/partner, and **ignoring the positive ones**, please rate how negative these feelings are:

H34.

Not At All Negative									Extremely Negative
1	2	3	4	5	6	7	8	9	10

17. The following questions concern your husband's involvement in your health care.

		<i>Never</i>				<i>Very Often</i>	
a.	How often does your husband/partner go with you to your appointments with doctors?	1	2	3	4	5	H35a.
b.	How often does your husband/partner talk with your doctor or other medical personnel about your risk for breast cancer?	1	2	3	4	5	H35b.
c.	How often does your husband/partner keep track of what you need to do about your risk for breast cancer?	1	2	3	4	5	H35c.
d.	How often does your husband/partner change his activities to assist you in your health care?	1	2	3	4	5	H35d.

18. Has your husband/partner attended individual, family or group sessions to become informed about your risk for breast cancer and what can be done? **H36.**

(1) Yes ☐ (5) No ☐

19. How much contact has your husband/partner had with medical personnel concerning your risk for breast cancer. **H37.**

Very Little or None							A lot
1	2	3	4	5	6	7	

20. Do you feel your husband/partner is adequately informed concerning your risk for breast cancer and what can be done about it? **H38.**

Not at All Very Much
1 2 3 4 5 6 7

21. To what extent are you satisfied with your husband/partner's involvement in your health care? H39.

Not at All 1 2 3 4 5 6 7 Very Much

MOOD SECTION

1. Have you **ever in your lifetime** had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? **I14**
- (1) ☐ Yes (5) ☐ No (Skip to Question 2)
- 1a. If there was such a two-week period, did your work or relationships suffer? **I14a.**
- (1) ☐ Yes (5) ☐ No
- 1b. If there was such a two-week period, did you get counseling or psychotherapy? **I14b.**
- (1) ☐ Yes (5) ☐ No
- 1c. If there was such a two-week period, did you get medication for this condition? **I14c.**
- (1) ☐ Yes (5) ☐ No
2. In **the past 6 months**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? **I12.**
- (1) ☐ Yes (5) ☐ No (Skip to Question 3)
- 2a. If there was such a two-week period in **the past 6 months**, did your work or relationships suffer? **I12a.**
- (1) ☐ Yes (5) ☐ No
- 2b. If there was such a two-week period in **the past 6 months**, did you get counseling or psychotherapy? **I12b.**
- (1) ☐ Yes (5) ☐ No
- 2c. If there was such a two-week period in **the past 6 months**, did you get medication for this condition? **I12c.**
- (1) ☐ Yes (5) ☐ No
3. Are you **currently** receiving counseling, psychotherapy or medication for depression or emotional problems? **I13.**
- (1) ☐ Yes (5) ☐ No

STRAIN SECTION

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the **Past Three Months**.*

		<u>Not at all</u>	<u>A little</u>	<u>Quite a bit</u>	<u>Extremely</u>	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energy--slowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

COPING SECTION

1. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of your risk for breast cancer. For each of the statements below, indicate the degree to which your life is affected positively by your risk of breast cancer.

		<i>Not At All</i>	<i>A Very Small Degree</i>	<i>A Small Degree</i>	<i>A Moderate Degree</i>	<i>A Great Degree</i>	<i>A Very Great Degree</i>	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e.
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h.
i.	A willingness to express my emotions.	1	2	3	4	5	6	L6i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6j.
k.	Appreciating each day.	1	2	3	4	5	6	L6k.
l.	Having compassion for others.	1	2	3	4	5	6	L6l.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n.

2. This set of questions deals with ways you've been coping with the stress in your life that comes with being at risk for breast cancer. There are many ways people try to deal with problems. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know *to what extent* you've been doing what the item says, how *much* or how *frequently*. Don't answer on the basis of whether it seems to be working but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>	
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4	L7a.
b.	I've been concentrating my efforts on doing something about my situation.	1	2	3	4	L7b.
c.	I've been saying to myself "this isn't possible."	1	2	3	4	L7c.
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4	L7d.
e.	I've been getting emotional support from others.	1	2	3	4	L7e.
f.	I've been giving up trying to deal with it.	1	2	3	4	L7f.
g.	I've been taking action to try to make the situation better.	1	2	3	4	L7g.
h.	I've been refusing to believe that it is possible that I have the gene.	1	2	3	4	L7h.
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	L7i.
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	L7j.
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4	L7k.
l.	I've been trying to come up with a strategy about what to do.	1	2	3	4	L7l.
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7m.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>	
n.	I've been giving up the attempt to cope.	1	2	3	4	L7n.
o.	I've been accepting the possibility that I might have the gene.	1	2	3	4	L7o.
p.	I've been expressing my negative feelings.	1	2	3	4	L7p.
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4	L7q.
r.	I've been learning to live with the possibility that I might have the gene.	1	2	3	4	L7r.
s.	I've been thinking hard about what steps to take.	1	2	3	4	L7s.
t.	I've been praying or meditating.	1	2	3	4	L7t.
u.	I've been making fun of the situation.	1	2	3	4	L7u.

3. The following items are to be answered only by those women who are married or living with a partner.

(-8) ☐ Not married or living with a partner

(Skip to Last Section on page 15, Background Data)

L8.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>	
a.	I've been denying or hiding my anger around my husband/partner.	1	2	3	4	L8a.
b.	I've been denying or hiding my worries around my husband/partner.	1	2	3	4	L8b.
c.	I've been avoiding talking about my problems around my husband/partner.	1	2	3	4	L8c.
d.	I've acted more positive around my husband/partner than I feel.	1	2	3	4	L8d.

BACKGROUND DATA

These are a few questions about your religious background, that we forgot to ask on the original questionnaire.

1. Religion: Catholic (1) ☐ Protestant (4) ☐ **A3.**
Jewish (2) ☐ Buddhist (5) ☐
Muslim (3) ☐ Other (6) ☐
None (7) ☐

- 1a. How often do you attend religious services? **A3a.**
(1) (5)
☐ Less Often Than Once a Month ☐ A Few Times A Month or More

- 1b. How important are religious and spiritual beliefs in your life? **A3b.**
Not at All Very Important
1 2 3 4 5

Once Again, We thank you for all of your valued participation in this study.



WOMEN'S HEALTH STUDY

Interim Questionnaire

As you may already know, there are two components to this breast cancer research--a study of the biology of genetics, which is now located at the University of Pennsylvania (previously it was at the University of Michigan) and a study of the personal and social aspects of genetic testing which is located at the University of Michigan. This questionnaire is part of the study of personal and social aspects. Some of these questions will be familiar. We are asking them again to learn more about how feelings and attitudes change over time.

If you have any questions about this questionnaire or research, please feel free to call me at 313-998-6560. For questions about the genetic testing component, you may call Kathleen Calzone at the University of Pennsylvania, 215-349-8141. Thank you very much for your valuable participation in this research.

Sean Bouvrette
Project Manager
Women's Health Study
University of Michigan

TODAY'S DATE _____

ID _____

INTERIM QUESTIONNAIRE - U

GENETIC TESTING-SECTION 1

1. Have you contributed a blood or tissue sample to the GENETIC TESTING portion of the research project?
☐ Yes ☐ No B21.

2. Has any member of your family contributed a blood or tissue sample to the GENETIC TESTING portion of the research project?
☐ Yes ☐ No ☐ I Don't Know B22.

3. Have you or any family members received notification that genetic results are available? B23.

There Has Been No Notification	Results Are Available	Results Are NOT YET Available	Results will NEVER BE Available, I am Not Eligible

4. Have **you** received results of genetic testing for breast or ovarian cancer?

☐ Yes ☐ No (Skip to Question 5)

4a. When did this occur? _____(mo/yr)

4b. What was the source of this information?

☐ University of Pennsylvania ☐ Independent Testing ☐ Other: _____

4c. What were the results? (Optional)

5. Has **any family member** received results of genetic testing for breast or ovarian cancer?

☐ Yes ☐ No (Skip to Next Section) ☐ Don't Know (Skip to Next Section)

5a. When did this occur? _____(mo/yr)

5b. What was the source of this information?

☐ University of Pennsylvania ☐ Independent Testing ☐ Other: _____

5c. What were the results? (Optional)

- 5d. Can you infer your genetic results from your relative's results (i.e., Have you been able to figure out whether you are positive or negative for the gene that conveys higher risk for breast cancer with this information?)

☐ Yes ☐ No ☐ Don't Know

PERSONAL ATTITUDES SECTION

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	There is nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
j.	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
l.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
o.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

GENETIC TESTING-SECTION 2

1. A medical test may soon be available that allows some women to learn their genetic risk for developing a form of breast and ovarian cancer that runs in families. Would you consider taking this genetic test?

(Please check one response).

B15.

- (1)._____ I will definitely take the test immediately when it becomes available.
 (2)._____ I will definitely take the test, but I am not sure if immediately.
 (3)._____ I will probably take the test immediately when it becomes available.
 (4)._____ I will probably take the test, but not immediately.
 (5)._____ I am undecided whether I will take the test
 (6)._____ I will probably not take the test.
 (7)._____ I will definitely not take the test.

2. On the following scale, indicate how distressing it is for you to know that you may be at increased risk for breast cancer because of your family history?

B66.

Not At All Distressing				Very Distressing
1	2	3	4	5

3. How distressing it is to be given the opportunity to be tested for the BRCA-1 gene, the altered gene associated with increased risk for breast cancer?

B67.

Not At All Distressing				Very Distressing
1	2	3	4	5

4. How distressed do you expect to be when you actually get tested for the BRCA-1 gene (before you receive results)?

B68.

Not At All Distressed				Very Distressed
1	2	3	4	5

5. How distressed would you be if you took the test and found that you **had** the BRCA-1 gene?

B69.

Not At All Distressed				Very Distressed
1	2	3	4	5

6. How distressed would you be if you took the test and found that you **did not have** the BRCA-1 gene? **B70.**

Not At All Distressed				Very Distressed	
1	2	3	4	5	

7. Overall, to what extent do you welcome the opportunity to be tested for the BRCA-1 gene? **B71.**

Not At All				Very Much So	
1	2	3	4	5	

		Not At All					All The Time		
8.	How often do you worry about developing breast cancer?	1	2	3	4	5			B27.
9.	To what extent do these worries interfere with your every day life?	1	2	3	4	5			B28.
10.	How often do you worry about having the altered gene carrying risk for breast cancer ?	1	2	3	4	5			B29.
11.	To what extent do these worries you have about having this altered gene interfere with your every day life?	1	2	3	4	5			B30.

12. When was the last time you had a mammography? **B32.**
 _____Month _____Year ⁽⁻⁸⁾ ☐ This question does not apply because of surgery.

13. How many times have you conducted a breast self-examinations (BSE) in the past six months? **B33.**
 _____times ⁽⁻⁸⁾ ☐ This question does not apply because of surgery.

14. How confident are you that you will perform breast self examination (BSE) ---

14a. --as **frequently** as needed? (-8) ☐ Does Not Apply Because of Surgery **B34a.**

Not at All Very Much So
1 2 3 4 5 6 7

14b. --as **carefully and competently** as needed? **B34b.**
(-8) ☐ Does Not Apply Because of Surgery

Not at All Very Much So
1 2 3 4 5 6 7

For each of the following areas of your life, you will be asked to make **two** ratings. First, indicate how much these decisions have been affected by the possibility that you have an increased risk for breast cancer (based on your family history). Second, how much would these decisions be affected by the results of genetic testing?

1	2	3	4	5
Not at all affected				Very much affected

		<u>Have been affected by being at risk for breast cancer</u>					<u>Would be affected by the results of genetic testing</u>					
15.	Decisions about having children	1	2	3	4	5	1	2	3	4	5	B35a B35b
16.	Decisions about form of birth control	1	2	3	4	5	1	2	3	4	5	B36a B36b
17.	Decisions about which steps to take to prevent the recurrence of breast cancer	1	2	3	4	5	1	2	3	4	5	B37a B37b
18.	Decisions about work and career	1	2	3	4	5	1	2	3	4	5	B38a B38b
19.	Decisions about savings and financial planning	1	2	3	4	5	1	2	3	4	5	B39a B39b
20.	Decisions about plans for the future	1	2	3	4	5	1	2	3	4	5	B40a B40b

21. Answer the following question only if you have (biological) daughters.

☐ Does Not Apply
(Skip to Question 22)

B41.

		<u>Have been affected by being at high risk for breast cancer</u>					<u>Would be affected by the results of genetic testing</u>					
a.	Plans for your daughter's future	1	2	3	4	5	1	2	3	4	5	B42

22. Do you feel you have enough information about breast cancer to make any decisions that might be necessary?

Not At All						Very Much	
1	2	3	4	5	6	7	

B43.

23. Do you feel you are adequately informed about the benefits and drawbacks of genetic testing for risk of breast cancer?

Not At All						Very Much	
1	2	3	4	5	6	7	

B44.

24. Do you feel you are adequately informed about what you could do to reduce your risk of breast cancer if you had the altered BRCA1 gene?

Not At All						Very Much	
1	2	3	4	5	6	7	

B45.

25. Do you feel you are adequately informed about the benefits and drawbacks of each option available to women who have the altered BRCA1 gene?

Not At All						Very Much	
1	2	3	4	5	6	7	

B46.

26. Do you feel you are adequately informed about what it would mean for your children if you had the altered BRCA1 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B47.

27. How confident are you that you:

- a. Will make the best decision in deciding whether to be tested for BRCA1, the altered gene associated with risk of breast cancer?

Not At All						Very Much
1	2	3	4	5	6	7

B48a.

- b. Would cope effectively with a finding that you had the altered BRCA1 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B48b.

- c. Would make the best decision concerning your options if you were found to have the altered BRCA1 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B48c.

- d. Would be able to follow through and cope effectively over the long haul if you were found to have the altered BRCA1 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B48d.

RELATIONSHIPS SECTION

1. Is there anyone in your life with whom you can share your most private feelings without holding back? **C21.**
(1) ☐ Yes (5) ☐ No
2. If married, can you share your most private feelings with your husband without holding back? **C21a.**
(1) ☐ Yes (5) ☐ No
3. If married, is there anyone besides your husband with whom you can share your most private feelings without holding back? **C21b.**
(1) ☐ Yes (5) ☐ No
-

LIFE EVENTS SECTION

1. Have any of the following events happened to you in the past six months? **D1(a-m)**
(Check All That Apply)
- | | |
|--|---|
| a. <input type="checkbox"/> You retired, were fired, or laid off from work. | g. <input type="checkbox"/> A close family member was seriously ill or injured. |
| b. <input type="checkbox"/> You were unemployed and looking for work. | h. <input type="checkbox"/> You had a marital separation or divorce. |
| c. <input type="checkbox"/> Your spouse retired, was fired, or laid off from work. | i. <input type="checkbox"/> You had serious troubles with relatives or close friends. |
| d. <input type="checkbox"/> Your spouse was unemployed and looking for work. | j. <input type="checkbox"/> Your spouse had troubles or difficulties with relatives or close friends. |
| e. <input type="checkbox"/> You had problems with the police or court. | k. <input type="checkbox"/> A close family member died. |
| f. <input type="checkbox"/> You got into serious financial difficulties. | l. <input type="checkbox"/> A close friend or relative died. |
| | m. <input type="checkbox"/> You were seriously ill or injured. |
-

MARRIAGE SECTION

The following questions apply to persons who are married or living with a partner. If you are not married or living with a partner, check the appropriate box and please skip to the Next Section, MOOD.

Not married or living with a partner ☐

E-a.

Most persons have disagreements in their relationships. Please check the appropriate box to indicate the extent of agreement or disagreement experienced between you and your partner **DURING THE PAST MONTH**, regarding.

		<i>Always Agree</i>	<i>Almost Always Agree</i>	<i>Occasionally Disagree</i>	<i>Frequently Disagree</i>	<i>Almost Always Disagree</i>	<i>Always Disagree</i>	
1.	Religious matters	6	5	4	3	2	1	H3.
2.	Demonstration of affection	6	5	4	3	2	1	H4.
3.	Sex relations	6	5	4	3	2	1	H6.
4.	Conventionality (correct or proper behavior)	6	5	4	3	2	1	H7.
5.	Making major decisions	6	5	4	3	2	1	H12.
6.	Career decisions	6	5	4	3	2	1	H15.

		<i>All of the time</i>	<i>Most of the time</i>	<i>More often than most</i>	<i>Occasionally</i>	<i>Rarely</i>	<i>Never</i>	
7.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6	H16.
8.	Do you ever regret that you married (or are living together)?	1	2	3	4	5	6	H20.
9.	How often do you and your husband/partner quarrel?	1	2	3	4	5	6	H21.
10.	How often do you and your husband/partner "get on each other's nerves?"	1	2	3	4	5	6	H22.

		<i>All of Them</i>	<i>Most of Them</i>	<i>Some of Them</i>	<i>Very few of Them</i>	<i>None of Them</i>
11.	Do you and your husband/partner engage in outside interests together?	5	4	3	2	1

H24.

How often would you say the following events occur between you and your husband/partner?

		<i>Never</i>	<i>Less than once a month</i>	<i>About twice a month</i>	<i>About twice a week</i>	<i>Once a day</i>	<i>More Often</i>
12.	Have a stimulating exchange of ideas	1	2	3	4	5	6
13.	Calmly discuss something	1	2	3	4	5	6
14.	Work together on a project	1	2	3	4	5	6

H25.

H27.

H28.

15. Considering **only the positive feelings** you have toward your husband/partner, and **ignoring the negative ones**, please rate how positive these feelings are:

H33.

Not At All Positive								Extremely Positive	
1	2	3	4	5	6	7	8	9	10

16. Considering **only the negative feelings** you have toward your husband/partner, and **ignoring the positive ones**, please rate how negative these feelings are:

H34.

Not At All Negative								Extremely Negative	
1	2	3	4	5	6	7	8	9	10

17. The following questions concern your husband's involvement in your health care.

		Never Very Often					
a.	How often does your husband/partner go with you to your appointments with doctors?	1	2	3	4	5	H35a.
b.	How often does your husband/partner talk with your doctor or other medical personnel about your risk for breast cancer?	1	2	3	4	5	H35b.
c.	How often does your husband/partner keep track of what you need to do about your risk for breast cancer?	1	2	3	4	5	H35c.
d.	How often does your husband/partner change his activities to assist you in your health care?	1	2	3	4	5	H35d.

18. Has your husband/partner attended individual, family or group sessions to become informed about your risk for breast cancer and what can be done? H36.

1
5
 Yes ☐ No ☐

19. How much contact has your husband/partner had with medical personnel concerning your risk for breast cancer. H37.

Very Little or None A lot
 1 2 3 4 5 6 7

20. Do you feel your husband/partner is adequately informed concerning your risk for breast cancer and what can be done about it? H38.

Not at All Very Much
 1 2 3 4 5 6 7

21. To what extent are you satisfied with your husband/partner's involvement in your health care? H39.

Not at All Very Much
 1 2 3 4 5 6 7

MOOD SECTION

1. Have you **ever in your lifetime** had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I14
- 1 5
- ☐ Yes ☐ No (Skip to Question 2)
- 1a. If there was such a two-week period, did your work or relationships suffer? I14a.
- 1 5
- ☐ Yes ☐ No
- 1b. If there was such a two-week period, did you get counseling or psychotherapy? I14b.
- 1 5
- ☐ Yes ☐ No
- 1c. If there was such a two-week period, did you get medication for this condition? I14c.
- 1 5
- ☐ Yes ☐ No
2. In **the past 6 months**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I12.
- 1 5
- ☐ Yes ☐ No (Skip to Question 3)
- 2a. If there was such a two-week period in **the past 6 months**, did your work or relationships suffer? I12a.
- 1 5
- ☐ Yes ☐ No
- 2b. If there was such a two-week period in **the past 6 months**, did you get counseling or psychotherapy? I12b.
- 1 5
- ☐ Yes ☐ No
- 2c. If there was such a two-week period in **the past 6 months**, did you get medication for this condition? I12c.
- 1 5
- ☐ Yes ☐ No
3. Are you **currently** receiving counseling, psychotherapy or medication for depression or emotional problems? I13.
- 1 5
- ☐ Yes ☐ No

STRAIN SECTION

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the **Past Three Months**.*

		<u>Not at all</u>	<u>A little</u>	<u>Quite a bit</u>	<u>Extremely</u>	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energy--slowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

COPING SECTION

1. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of your risk for breast cancer. For each of the statements below, indicate the degree to which your life is affected positively by your risk of breast cancer.

		<i>Not At All</i>	<i>A Very Small Degree</i>	<i>A Small Degree</i>	<i>A Moderate Degree</i>	<i>A Great Degree</i>	<i>A Very Great Degree</i>	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e.
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h.
i.	A willingness to express my emotions.	1	2	3	4	5	6	L6i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6j.
k.	Appreciating each day.	1	2	3	4	5	6	L6k.
l.	Having compassion for others.	1	2	3	4	5	6	L6l.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n.

2. This set of questions deals with ways you've been coping with the stress in your life that comes with being at risk for breast cancer. There are many ways people try to deal with problems. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know *to what extent* you've been doing what the item says, how *much* or how *frequently*. Don't answer on the basis of whether it seems to be working but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>	
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4	L7a.
b.	I've been concentrating my efforts on doing something about my situation.	1	2	3	4	L7b.
c.	I've been saying to myself "this isn't possible."	1	2	3	4	L7c.
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4	L7d.
e.	I've been getting emotional support from others.	1	2	3	4	L7e.
f.	I've been giving up trying to deal with it.	1	2	3	4	L7f.
g.	I've been taking action to try to make the situation better.	1	2	3	4	L7g.
h.	I've been refusing to believe that it is possible that I have the gene.	1	2	3	4	L7h.
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	L7i.
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	L7j.
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4	L7k.
l.	I've been trying to come up with a strategy about what to do.	1	2	3	4	L7l.
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7m.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>
n.	I've been giving up the attempt to cope.	1	2	3	4
o.	I've been accepting the possibility that I might have the gene.	1	2	3	4
p.	I've been expressing my negative feelings.	1	2	3	4
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
r.	I've been learning to live with the possibility that I might have the gene.	1	2	3	4
s.	I've been thinking hard about what steps to take.	1	2	3	4
t.	I've been praying or meditating.	1	2	3	4
u.	I've been making fun of the situation.	1	2	3	4

L7n.

L7o.

L7p.

L7q.

L7r.

L7s.

L7t.

L7u.

3. The following items are to be answered only by those women who are married or living with a partner.

☐ Not married or living with a partner

L8.

(Skip to Last Section on page 15, Background Data)

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>
a.	I've been denying or hiding my anger around my husband/partner.	1	2	3	4
b.	I've been denying or hiding my worries around my husband/partner.	1	2	3	4
c.	I've been avoiding talking about my problems around my husband/partner.	1	2	3	4
d.	I've acted more positive around my husband/partner than I feel.	1	2	3	4

L8a.

L8b.

L8c.

L8d.

BACKGROUND DATA

These are a few questions about your religious background, that we forgot to ask on the original questionnaire.

1. Religion: Catholic (1) ☐ Protestant (4) ☐ A3.
Jewish (2) ☐ Buddhist (5) ☐
Muslim (3) ☐ Other (6) ☐
None (7) ☐

- 1a. How often do you attend religious services? A3a.
(1) (5)
☐ Less Often Than Once a Month ☐ A Few Times A Month or More

- 1b. How important are religious and spiritual beliefs in your life? A3b.
Not at All Very Important
1 2 3 4 5

Once Again, We thank you for all of your valued participation in this study.

☐ ☐ ☐ ☐ - ☐



WOMEN'S HEALTH STUDY

Spouse/Partner Questionnaire

Today's Date _____

A-ID _____

SPOP

BACKGROUND DATA SECTION

1. Date of Birth _____ Month _____ Day _____ Year **A1.**
2. Ethnic Background: White ☐ 1 Black ☐ 4 **A2.**
 Hispanic ☐ 2 Asian ☐ 5
 Native American ☐ 3 Other ☐ 6
3. Religion: Catholic ☐ 1 Protestant ☐ 4 **A3.**
 Jewish ☐ 2 Buddhist ☐ 5
 Muslim ☐ 3 Other ☐ 6
 None ☐ 7
- 3a. How often do you attend religious services? **A3a.**
☐ 1 Less Than Once a Month ☐ 5 A Few Times A Month or More
- 3b. How important are religious and spiritual beliefs in your life? **A3b.**
Not at All 1 2 3 4 5 Very Important
4. Are you currently working for pay outside the home? Yes ☐ 1 No ☐ 5 **A7.**
5. If **yes**, about how many hours per week are you working for pay? **A8.**
Less than 10 10-20 21-30 31-40 41 or more
☐ ☐ ☐ ☐ ☐
(1) (2) (3) (4) (5)
6. What is the highest level of education you have completed? (**Check one**) **A9.**
1 ☐ Less than 9th grade 5 ☐ Completed college
2 ☐ Dropped out of high school 6 ☐ Some graduate or professional training
3 ☐ Completed high school 7 ☐ Completed graduate or professional training
4 ☐ Some college

The following two questions are optional, but we hope that you will provide this information.
Please check the appropriate box. (**Check one**)

7. What is your household's total income? (**Check one**) **A10.**
(1) ☐ Less than \$10,000 (4) ☐ \$30,000 to \$39,999 (7) ☐ \$60,000 to \$69,999
(2) ☐ \$10,000 to \$19,999 (5) ☐ \$40,000 to \$49,999 (8) ☐ Greater than \$69,999
(3) ☐ \$20,000 to \$29,999 (6) ☐ \$50,000 to \$59,999
8. How many people (adults and children) does this income support? _____ **A11.**

PERSONAL ATTITUDES SECTION

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	There is nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
j.	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
l.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
o.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

HEALTH SECTION

The following questions concern your wife/partner's risk of developing breast cancer again and of her having the altered gene which has been found to be associated with increased risk for breast cancer. As you may know, breast cancer runs in certain families. In some of these families, persons who develop cancer have an altered version of a gene, BRCA1. Some family members will inherit the gene and others will not.

		<div style="display: flex; justify-content: space-between; width: 100%;"> <i>Not At All</i> <i>All The Time</i> </div>					
1.	How often do you worry about your wife/partner again developing breast cancer?	1	2	3	4	5	B27.
2.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B28.
3.	How often do you worry about your wife/partner having the altered gene associated with risk for breast cancer?	1	2	3	4	5	B29.
4.	To what extent do worries about your wife/partner having this altered gene interfere with your every day life?	1	2	3	4	5	B30.
5.	How often do you worry about developing cancer yourself?	1	2	3	4	5	B31.

6. How likely do you think your wife/partner is to develop breast cancer again in the near future? **B9.**
(Please circle one).

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

7. Overall, what do you believe your wife/partner's risk is of developing breast cancer again at some point in her lifetime? **B10.**

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

8. Overall, what do you believe your wife/partner's risk is of developing some other cancer unrelated to breast cancer at some point in her lifetime? **B14.**

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

9. How often does your wife/partner express concern and seek support from you about the risk of breast cancer to herself and women in her family? **B49.**

Never	Rarely	Sometimes	Often
1	2	3	4

10. How much of a burden is this on you? **B50.**

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

11. How often do you discuss genetic testing for breast cancer with your wife/partner? **B51.**

Never	Rarely	Sometimes	Often
1	2	3	4

12. When you have these discussions, who generally initiates them? **B52.**

You	Your Wife/partner	Equally
1	2	3

13. How satisfied are you with these discussions? **B53.**

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

14. How often do you and your wife/partner get into a disagreement or conflict over the issue of her getting genetic testing for the risk of breast cancer? **B54.**

Never	Rarely	Sometimes	Often
1	2	3	4

15. Do you think it is beneficial to have genetic testing for risk of breast cancer available to women? **B55.**

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

16. Do you want your wife/partner to get genetic testing for risk of breast cancer? **B56.**

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

22a. Overall, do you feel you are adequately informed concerning your wife/partner's risk for cancer and what can be done about it? **B43a.**

Not at All Very Much
1 2 3 4 5 6 7

22b. Do you feel you are adequately informed about your wife/partner's risk for developing breast cancer **again**? **B43b.**

Not at All Very Much
1 2 3 4 5 6 7

22c. Do you feel you are adequately informed about the benefits and drawbacks of genetic testing for risk of breast cancer? **B44.**

Not at All Very Much
1 2 3 4 5 6 7

22d. Do you feel you are adequately informed about what your wife/partner could do personally to reduce her risk of breast cancer if she had the altered BRCA1 gene? **B45.**

Not at All Very Much
1 2 3 4 5 6 7

22e. Do you feel you are adequately informed about the benefits and drawbacks of options available to women who have the altered BRCA1 gene? **B46.**

Not at All Very Much
1 2 3 4 5 6 7

22f. Do you feel you are adequately informed about what it would mean for your children if your wife/partner had the altered BRCA1 gene? ☐ **Check here if you do not have children.** **B47.**

(-8)
Not at All Very Much
1 2 3 4 5 6 7

C-22f.

23. How confident are you that your wife/partner:

23a. Will make the best decision about whether to be tested for BRCA1, the altered gene associated with risk of breast cancer? **B48a.**

Not at All Very Much
1 2 3 4 5 6 7

23b. Would cope effectively with the finding that she had the altered BRCA1 gene? **B48b.**

Not at All Very Much
1 2 3 4 5 6 7

23c. Would make the best decision concerning her options if she were found to have the altered BRCA1 gene?

Not at All 1 2 3 4 5 6 7 Very Much

B48d.

Not at All Very Much
1 2 3 4 5 6 7

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		<i>I Don't Know</i>	
a.	Mammography is effective in the early detection of breast cancer in women.	1	2	3	4	5	9	B20a.
b.	Breast cancer that is detected early is curable.	1	2	3	4	5	9	B20b.
c.	Mammography can detect lumps that cannot be felt by a woman or by her doctor.	1	2	3	4	5	9	B20c.
d.	If more women went for breast screening, there would be fewer deaths from breast cancer.	1	2	3	4	5	9	B20d.
e.	If a lump is found in a woman's breast, it is usually too late to do anything about it.	1	2	3	4	5	9	B20f.
f.	There are so many things that could happen to someone's health that it is pointless for a woman to worry about breast cancer.	1	2	3	4	5	9	B20i.
g.	If a woman were found to have breast cancer, the chances of it being cured are high.	1	2	3	4	5	9	B20m.
h.	Once a woman has had effective treatment for breast cancer, she will not get it again.	1	2	3	4	5	9	B20n.
i.	A mastectomy totally eliminates a woman's risk for breast cancer.	1	2	3	4	5	9	B20o.
j.	All women who have the altered version of the BRCA1 gene will get breast cancer.	1	2	3	4	5	9	B20p.
k.	Most of the breast cancer in the United States is due to altered versions of the BRCA1 gene.	1	2	3	4	5	9	B20q.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		<i>I Don't Know</i>
l.	The next decade is going to bring major advances in the detection and treatment of breast cancer.	1	2	3	4	5	9
m.	Over the next decade, medical break-through's are going to make breast cancer much less of a threat to women's health.	1	2	3	4	5	9

B20r.

B20s.

25. If your wife/partner were to take the test and find that she **did not** have the altered version of the BRCA1 gene which is associated with high risk for breast cancer, what would you expect your reactions to be?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
a.	I would feel wonderful.	1	2	3	4	5
b.	I would feel I had been told what I knew all along.	1	2	3	4	5
c.	I would feel relieved.	1	2	3	4	5
d.	I would not believe the results.	1	2	3	4	5
e.	I would fall apart emotionally.	1	2	3	4	5
f.	I would feel guilty.	1	2	3	4	5
g.	I would still feel anxious.	1	2	3	4	5
h.	I would feel angry.	1	2	3	4	5
i.	I would feel prepared for the future.	1	2	3	4	5
j.	I would feel I had done all I needed to do.	1	2	3	4	5
k.	I would not feel very differently.	1	2	3	4	5

B18a.

B18b.

B18c.

B18d.

B18e.

B18f.

B18g.

B18h.

B18i.

B18j.

B18k.

26. If your wife/partner were to take the test and find out that she **had** the altered version of the BRCA1 gene for breast cancer, what would you expect your reactions to be?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
a.	I would feel relieved about being more certain.	1	2	3	4	5
b.	I would feel I had been told what I knew all along.	1	2	3	4	5
c.	I would not believe the results.	1	2	3	4	5
d.	I would feel guilty.	1	2	3	4	5
e.	I would feel depressed.	1	2	3	4	5

B19a.

B19b.

B19c.

B19d.

B19e.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
f.	I would feel worried about the future.	1	2	3	4	5	B19f.
g.	I would fall apart emotionally.	1	2	3	4	5	B19g.
h.	I would feel anxious.	1	2	3	4	5	B19h.
i.	I would feel angry.	1	2	3	4	5	B19i.
j.	I would not feel very differently.	1	2	3	4	5	B19j.
k.	I would want my daughters to be tested as soon as possible.	1	2	3	4	5	B19k.

27. The following questions concern your involvement in your wife/partner's health care:

		<i>Not at All</i>			<i>Very Often</i>		
a.	To what extent do you go with your wife/partner to her appointments with doctors?	1	2	3	4	5	H35a.
b.	To what extent do you talk with your wife/partner's doctor or other medical personnel about her risk of cancer?	1	2	3	4	5	H35b.
c.	To what extent do you keep track of what your wife/partner needs to do about her risk of cancer?	1	2	3	4	5	H35c.
d.	To what extent do you change your activities to look after your wife/partner?	1	2	3	4	5	H35d.

28. If my wife/partner were tested and found to have the altered BRCA1 gene carrying increased risk of breast cancer, I would want her to manage her risk by relying:

- a. Being extra careful about breast self-examination and regular medical examinations. **B64a.**

Not at All						Very Much So
1	2	3	4	5	6	7

- b. Getting preventive surgery. **B64b.**

Not at All						Very Much So
1	2	3	4	5	6	7

29. I do not believe it would be my place to tell my wife/partner my opinion about what she should do about her risk of breast cancer.

B65.

Strongly Disagree						Strongly Agree
1	2	3	4	5	6	7

RELATIONSHIPS

1. Is there anyone in your life with whom you can share your most private feelings without holding back? **C21.**

(1) ☐ Yes (5) ☐ No

2. Can you share your most private feelings with your wife/partner without holding back? **C21a.**

(1) ☐ Yes (5) ☐ No

3. Is there anyone besides your wife/partner with whom you can share your most private feelings without holding back? **C21b.**

(1) ☐ Yes (5) ☐ No

4. Have any of the events listed below happened to you in the past six months? **D1 (a-m)**
(Check All That Apply)

- | | |
|---|---|
| <p>a. <input type="checkbox"/> You retired or were fired or laid off from work.</p> <p>b. <input type="checkbox"/> You were unemployed and looking for work.</p> <p>c. <input type="checkbox"/> Your spouse retired or was fired or laid off from work.</p> <p>d. <input type="checkbox"/> Your spouse was unemployed and looking for work.</p> <p>e. <input type="checkbox"/> You had problems with the police or court.</p> <p>f. <input type="checkbox"/> You got into serious financial difficulties.</p> | <p>g. <input type="checkbox"/> A close family member was seriously ill or injured.</p> <p>h. <input type="checkbox"/> You had a marital separation or divorce.</p> <p>i. <input type="checkbox"/> You had serious troubles with relatives or close friends.</p> <p>j. <input type="checkbox"/> Your spouse had troubles with relatives or close friends.</p> <p>k. <input type="checkbox"/> A close family member died.</p> <p>l. <input type="checkbox"/> A close friend or relative died.</p> <p>m. <input type="checkbox"/> You were seriously ill or injured.</p> |
|---|---|

MARRIAGE SECTION

Most people have disagreements in their relationships. Please indicate, using check marks the extent of agreement or disagreement experienced between you and your wife/partner on the following issues **DURING THE PAST MONTH.**

		<i>Always Agree</i>	<i>Almost Always Agree</i>	<i>Occa- sionally Disagree</i>	<i>Fre- quently Disagree</i>	<i>Almost Always Disagree</i>	<i>Always Disagree</i>	
1.	Handling family finances	1	2	3	4	5	6	H1.
2.	Matters of recreation	1	2	3	4	5	6	H2.
3.	Religious matters	1	2	3	4	5	6	H3.
4.	Demonstration of affection	1	2	3	4	5	6	H4.
5.	Friends	1	2	3	4	5	6	H5.
6.	Sex relations	1	2	3	4	5	6	H6.
7.	Conventionality (correct or proper behavior)	1	2	3	4	5	6	H7.
8.	Philosophy of life	1	2	3	4	5	6	H8.
9.	Ways of dealing with parents or in-laws	1	2	3	4	5	6	H9.
10.	Aims, goals, and things believed important	1	2	3	4	5	6	H10.
11.	Amount of time spent together	1	2	3	4	5	6	H11.
12.	Making major decisions	1	2	3	4	5	6	H12.
13.	Household tasks	1	2	3	4	5	6	H13.
14.	Leisure time interests and activities	1	2	3	4	5	6	H14.
15.	Career decisions	1	2	3	4	5	6	H15.

		<i>All of the Time</i>	<i>Most of the Time</i>	<i>More Often than Most</i>	<i>Occa- sionally</i>	<i>Rarely</i>	<i>Never</i>
16.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6
17.	How often do you or your wife/partner leave the house after a fight?	1	2	3	4	5	6
18.	In general, how often do you think that things between you and your wife/partner are going well?	1	2	3	4	5	6
19.	Do you confide in your wife/partner?	1	2	3	4	5	6
20.	Do you ever regret that you married (or lived together)?	1	2	3	4	5	6
21.	How often do you and your wife/partner quarrel?	1	2	3	4	5	6
22.	How often do you and your wife/partner "get on each other's nerves?"	1	2	3	4	5	6

H16.

H17.

H18.

H19.

H20.

H21.

H22.

		<i>Every Day</i>	<i>Almost Every Day</i>	<i>Occa- sionally</i>	<i>Rarely</i>	<i>Never</i>
23.	Do you kiss your wife/partner?	1	2	3	4	5

H23.

		<i>All of Them</i>	<i>Most of Them</i>	<i>Some of Them</i>	<i>Very few of Them</i>	<i>None of Them</i>
24.	Do you and your wife/partner engage in outside interests together?	1	2	3	4	5

H24.

How often would you say the following events occur between you and your wife/partner?

		<i>Never</i>	<i>Less than once a month</i>	<i>About twice a month</i>	<i>About twice a week</i>	<i>Once a day</i>	<i>More Often</i>
25.	Have a stimulating exchange of ideas	1	2	3	4	5	6
26.	Laugh together	1	2	3	4	5	6
27.	Calmly discuss something	1	2	3	4	5	6
28.	Work together on a project	1	2	3	4	5	6

H25.

H26.

H27.

H28.

These are some things couples sometimes agree and sometimes disagree upon. Indicate if either item below caused differences of opinions or were problems in your relationship during the past month. **(Check yes or no).**

29. Being too tired for sex. (1) ☐ Yes (5) ☐ No

H29.

30. Not showing love. (1) ☐ Yes (5) ☐ No

H30.

31. The following scale represents different degrees of happiness in your relationship. The middle point "happy" represents the degree of happiness of most relationships. Please circle the number which best describes the degree of happiness, all things considered, of your relationship.

H31.

Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect
1	2	3	4	5	6	7

32. Please check one of the following statements to best describe how you feel about the **future** of your relationship.

H32.

- (1).___ I want desperately for my relationship to succeed, and would go to almost any length to see that it does.
- (2).___ I want very much for my relationship to succeed, and will do all I can to see that it does.
- (3).___ I want very much for my relationship to succeed, and will do my fair share to see that it does.
- (4).___ It would be very nice if my relationship succeeded, but I can't do much more than I am doing now to help it succeed.
- (5).___ It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.
- (6).___ My relationship can never succeed, and there is no more that I can do to keep the relationship going.

33. Considering **only the positive feelings** you have toward your wife/partner, and **ignoring the negative ones**, please rate how positive these feelings are: H33.

Not At All Positive					Extremely Positive				
1	2	3	4	5	6	7	8	9	10

34. Considering **only the negative feelings** you have toward your wife/partner, and **ignoring the positive ones**, please rate how negative these feelings are: H34.

Not At All Negative					Extremely Negative				
1	2	3	4	5	6	7	8	9	10

CURRENT FAMILY SECTION

Please indicate the extent to which each of the following items describes your current family (your household).

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
1.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5	M1.
2.	In times of crisis we can turn to each other for support.	1	2	3	4	5	M2.
3.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5	M3.
4.	Individuals are accepted for who they are.	1	2	3	4	5	M4.
5.	We avoid discussing our fears and concerns.	1	2	3	4	5	M5.
6.	We can express feelings to each other.	1	2	3	4	5	M6.
7.	There are lots of bad feelings in the family.	1	2	3	4	5	M7.
8.	We feel accepted for who we are.	1	2	3	4	5	M8.
9.	Making decisions is a problem for our family.	1	2	3	4	5	M9.
10.	We are able to make decisions about how to solve problems.	1	2	3	4	5	M10.
11.	We don't get along well together.	1	2	3	4	5	M11.
12.	We confide in each other.	1	2	3	4	5	M12.

YOUR HEALTH AND MOOD SECTION

1. In general, would you say your health is: **I11.**
- (1) ☐ Excellent (2) ☐ Very Good (3) ☐ Good (4) ☐ Fair (5) ☐ Poor
2. Have you **ever in your life** had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? **I14.**
- (1) ☐ Yes (5) ☐ No (Skip to Question 3)
- 2a. If there was such a two-week period, did your work or relationships suffer? **I14a.**
- (1) ☐ Yes (5) ☐ No
- 2b. If there was such a two-week period, did you get counseling or psychotherapy? **I14b.**
- (1) ☐ Yes (5) ☐ No
- 2c. If there was such a two-week period, did you get medication for this condition? **I14c.**
- (1) ☐ Yes (5) ☐ No
3. In **the past 6 months**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? **I12.**
- (1) ☐ Yes (5) ☐ No (Skip to Question 4)
- 3a. If there was such a two-week period (**in the past 6 months**), did your work or relationships suffer? **I12a.**
- (1) ☐ Yes (5) ☐ No
- 3b. If there was such a two-week period (**in the past 6 months**), did you get counseling or psychotherapy? **I12b.**
- (1) ☐ Yes (5) ☐ No
- 3c. If there was such a two-week period, (**in the past 6 months**) did you get medication for this problem? **I12c.**
- (1) ☐ Yes (5) ☐ No
4. Are you **currently** receiving counseling, psychotherapy, or medication for depression or emotional problems? **I13.**
- (1) ☐ Yes (5) ☐ No

SYMPTOMS OF STRAIN SECTION

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the **Past Three Months**.*

		<i>1</i> <i>Not at all</i>	<i>2</i> <i>A little</i>	<i>3</i> <i>Quite a bit</i>	<i>4</i> <i>Extremely</i>	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energy--slowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

COPING SECTION

1. Imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do? Please answer **yes** or **no** for each choice.

		YES	NO	
a.	I would ask the dentist exactly what s/he was going to do.	1	5	L1_1
b.	I would take a tranquilizer or have a drink before going.	1	5	L1_2
c.	I would try to think about pleasant memories.	1	5	L1_3
d.	I would want the dentist to tell me when I would feel pain.	1	5	L1_4
e.	I would try to sleep.	1	5	L1_5
f.	I would watch all the dentist's movements and listen for the sound of the drill.	1	5	L1_6
g.	I would watch the flow of water from my mouth to see if it contained blood.	1	5	L1_7
h.	I would do mental puzzles in my mind.	1	5	L1_8

2. Imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do?

		YES	NO	
a.	I would sit by myself and have as many daydreams and fantasies as I could.	1	5	L2_1
b.	I would stay alert and try to keep myself from falling asleep.	1	5	L2_2
c.	I would exchange life stories with the other hostages.	1	5	L2_3
d.	If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing.	1	5	L2_4
e.	I would watch every movement of my captors and keep an eye on their weapons.	1	5	L2_5
f.	I would try to sleep as much as possible.	1	5	L2_6
g.	I would think about how nice it's going to be when I get home.	1	5	L2_7
h.	I would make sure I knew where every possible exit was.	1	5	L2_8

3. Imagine that due to a large drop in sales, it is rumored that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about lay-off has been made and will be announced in several days. Please answer **yes** or **no** for each choice.

		YES	NO	
a.	I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said.	1	5	L3_1
b.	I would review the list of duties for my present job and try to figure out if I had fulfilled them all.	1	5	L3_2
c.	I would go to the movies to take my mind off things.	1	5	L3_3
d.	I would try to remember any arguments or disagreements I might have had with the supervisor that would have lowered his opinion of me.	1	5	L3_4
e.	I would push all thoughts of being laid off out of my mind.	1	5	L3_5
f.	I would tell my spouse that I'd rather not discuss my chances of being laid off.	1	5	L3_6
g.	I would try to think which employees in my department the supervisor might have thought had done the worst job.	1	5	L3_7
h.	I would continue doing my work as if nothing special was happening.	1	5	L3_8

4. Imagine that you are on an airplane, 30 minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced that all is well. Please answer **yes** or **no** for each choice.

		YES	NO	
a.	I would carefully read the information provided about safety features in the plane and make sure I knew where the emergency exits were.	1	5	L4_1
b.	I would make small talk with the passenger beside me.	1	5	L4_2
c.	I would watch the end of the movie, even if I had seen it before.	1	5	L4_3
d.	I would call for the flight attendant and ask her/him exactly what the problem was.	1	5	L4_4
e.	I would order a drink or tranquilizer from the stewardess.	1	5	L4_5
f.	I would listen carefully to the engines for unusual noises and would watch the crew to see if their behavior was out of the ordinary.	1	5	L4_6
g.	I would talk to the passenger beside me about what might be wrong.	1	5	L4_7
h.	I would settle down and read a book or magazine or write a letter.	1	5	L4_8

5. This set of questions deals with ways you've been coping with the stress in your life that goes with your wife/partner possibly having the altered BRCA1 gene associated with risk for breast cancer. Obviously, different people deal with this stress in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know *to what extent* you've been doing what the item says, how *much* or how *frequently*. Don't answer on the basis of whether it seems to be working, but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>	
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4	L7_a.
b.	I've been concentrating my efforts on doing something about her situation.	1	2	3	4	L7_b.
c.	I've been saying to myself "this isn't possible."	1	2	3	4	L7_c.
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4	L7_d.
e.	I've been getting emotional support from others.	1	2	3	4	L7_e.
f.	I've been giving up trying to deal with it.	1	2	3	4	L7_f.
g.	I've been taking action to try to make the situation better.	1	2	3	4	L7_g.
h.	I've been refusing to believe that it is possible she has the gene.	1	2	3	4	L7_h.
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	L7_i.
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	L7_j.
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4	L7_k.
l.	I've been trying to come up with a strategy for what to do.	1	2	3	4	L7_l.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>	
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7_m.
n.	I've been giving up the attempt to cope.	1	2	3	4	L7_n.
o.	I've been accepting the possibility that she might have the gene.	1	2	3	4	L7_o.
p.	I've been expressing my negative feelings.	1	2	3	4	L7_p.
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4	L7_q.
r.	I've been learning to live with the possibility she might have the gene.	1	2	3	4	L7_r.
s.	I've been thinking hard about what steps to take.	1	2	3	4	L7_s.
t.	I've been praying or meditating.	1	2	3	4	L7_t.
u.	I've been making fun of the situation.	1	2	3	4	L7_u.
v.	I've been giving pep talks and encouraging my wife/partner.	1	2	3	4	L7_v.
w.	I've been denying or hiding my anger around my wife/partner.	1	2	3	4	L7_w.
x.	I've been denying or hiding my own worries around my wife/partner.	1	2	3	4	L7_x.
y.	I've been trying to give my wife/partner opportunities to talk about her worries.	1	2	3	4	L7_y.
z.	I've been trying to find out what my wife/partner is feeling.	1	2	3	4	L7_z.
aa.	I've been avoiding talking about my own problems around my wife/partner.	1	2	3	4	L7_aa.
bb.	I've acted more positive around my wife/partner than I feel.	1	2	3	4	L7_bb.

The following questions concern coping with your wife/partner's diagnosis and treatment for cancer:

6. **At your worst**, how distressed did you feel about your wife/partner's diagnosis and treatment of cancer? **L8.**

Not at All Very Much
1 2 3 4 5 6 7

7. During that time, did you ever have two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually like to do for fun? **L9.**
- (1) ☐ Yes (5) ☐ No (Skip to Question 8)

- a. If there was such a two-week period, did your work or relationships suffer? **L9a.**
- (1) ☐ Yes (5) ☐ No

- b. If there was such a two-week period, did you get counseling or psychotherapy? **L9b.**
- (1) ☐ Yes (5) ☐ No

- c. If there was such a two-week period, did you get medication for this problem? **L9c.**
- (1) ☐ Yes (5) ☐ No

8. For each of the statements on the following page, indicate the degree to which this change occurred in your life as a result of your wife/partner being diagnosed and treated for breast cancer. Please use the following scale:

- 1 = I experienced **no** change as a result of my wife/partner's being diagnosed and treated for cancer.
- 2 = I experienced this change to a **very small degree** as a result of my wife/partner's being diagnosed and treated for cancer.
- 3 = I experienced this change to a **small degree** as a result of my wife/partner's being diagnosed and treated for cancer.
- 4 = I experienced this change to a **moderate degree** as a result of my wife/partner's being diagnosed and treated for cancer.
- 5 = I experienced this change to a **great degree** as a result of my wife/partner's being diagnosed and treated for cancer.
- 6 = I experienced this change to a **very great degree** as a result of my wife/partner's being diagnosed and treated for cancer.

- ☐ Does not apply because I was not with my wife/partner when she was being treated for breast cancer. **L6.**

		<i>No Change</i>	<i>Very Small Degree</i>	<i>Small Degree</i>	<i>Moderate Degree</i>	<i>Great Degree</i>	<i>Very Great Degree</i>	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6_a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6_b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6_c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6_d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6_e.
f.	Knowing that I can count on people in times of trouble.	1	2	3	4	5	6	L6_f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6_g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6_h.
i.	A willingness to express my emotions.	1	2	3	4	5	6	L6_i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6_j.
k.	Appreciating each day.	1	2	3	4	5	6	L6_k.
l.	Having compassion for others.	1	2	3	4	5	6	L6_l.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6_m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6_n.

9. During the time in which your wife/partner was being treated for breast cancer, how often did you do the following to help her manage the emotional distress?

☐ Does not apply because I was not with my wife/partner when
(-8) she was being treated for breast cancer.

		<i>Never</i>					<i>Very Often</i>	
		1	2	3	4	5		
1.	Gave her advice?	1	2	3	4	5		L10a.
2.	Went out of your way not to upset her?	1	2	3	4	5		L10b.
3.	Agreed with her to avoid an argument?	1	2	3	4	5		L10c.
4.	Acted more optimistic than you felt?	1	2	3	4	5		L10d.
5.	Kept your own problems to yourself?	1	2	3	4	5		L10e.
6.	Made up after an argument more quickly than before?	1	2	3	4	5		L10f.
7.	Apologized even when you didn't feel you were wrong?	1	2	3	4	5		L10g.
8.	Told her to calm down or relax?	1	2	3	4	5		L10h.
9.	Hid information that may upset her?	1	2	3	4	5		L10i.
10.	Stayed out of her problems?	1	2	3	4	5		L10j.
11.	Let your own problems take a "back seat" to her needs?	1	2	3	4	5		L10k.
12.	Gave her space when she was upset?	1	2	3	4	5		L10l.

We thank you for all of your valued participation in this study.



WOMEN'S HEALTH STUDY

Spouse/Partner Questionnaire

Today's Date _____

U-ID _____

SPOP

BACKGROUND DATA SECTION

1. Date of Birth _____Month _____Day _____Year **A 1.**
2. Ethnic Background: White ☐ 1 Black ☐ 4 **A 2.**
Hispanic ☐ 2 Asian ☐ 5
Native American ☐ 3 Other ☐ 6
3. Religion: Catholic ☐ 1 Protestant ☐ 4 **A 3.**
Jewish ☐ 2 Buddhist ☐ 5
Muslim ☐ 3 Other ☐ 6
None ☐ 7
- 3a. How often do you attend religious services? **A 3a.**
☐ 1 Less Than Once a Month ☐ 5 A Few Times A Month or More
- 3b. How important are religious and spiritual beliefs in your life? **A 3b.**
Not at All 1 2 3 4 5 Very Important
4. Are you currently working for pay outside the home? Yes ☐ 1 No ☐ 5 **A 7.**
5. If **yes**, about how many hours per week are you working for pay? **A 8.**
Less than 10 10-20 21-30 31-40 41 or more
☐ ☐ ☐ ☐ ☐
(1) (2) (3) (4) (5)
6. What is the highest level of education you have completed? **(Check one)** **A 9.**
1 ☐ Less than 9th grade 5 ☐ Completed college
2 ☐ Dropped out of high school 6 ☐ Some graduate or professional training
3 ☐ Completed high school 7 ☐ Completed graduate or professional training
4 ☐ Some college
- The following two questions are optional**, but we hope that you will provide this information.
Please check the appropriate box. **(Check one)**
7. What is your household's total income? **(Check one)** **A 10.**
(1) ☐ Less than \$10,000 (4) ☐ \$30,000 to \$39,999 (7) ☐ \$60,000 to \$69,999
(2) ☐ \$10,000 to \$19,999 (5) ☐ \$40,000 to \$49,999 (8) ☐ Greater than \$69,999
(3) ☐ \$20,000 to \$29,999 (6) ☐ \$50,000 to \$59,999
8. How many people (adults and children) does this income support? _____ **A 11.**

PERSONAL ATTITUDES SECTION

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	Nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
j.	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
l.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
o.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

HEALTH SECTION

The following questions concern your wife/partner's risk of developing breast cancer and of her having the altered gene which has been found to be associated with increased risk for breast cancer. As you may know, breast cancer runs in certain families. In some of these families, persons who develop cancer have an altered version of a gene, BRCA1. Some family members will inherit the gene and others will not.

		<i>Not At All</i>			<i>All The Time</i>		
1.	How often do you worry about your wife/partner developing breast cancer?	1	2	3	4	5	B27.
2.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B28.
3.	How often do you worry about your wife/partner having the altered gene associated with risk for breast cancer?	1	2	3	4	5	B29.
4.	To what extent do worries about your wife/partner having this altered gene interfere with your every day life?	1	2	3	4	5	B30.
5.	How often do you worry about developing cancer yourself?	1	2	3	4	5	B31.

6. How likely do you think your wife/partner is to develop breast cancer in **the near future?** B9.
(Please circle one).

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

7. Overall, what do you believe your wife/partner's risk is of developing breast cancer **at some point in her lifetime?** B10.

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

8. Overall, what do you believe your wife/partner's risk is of developing some other cancer **unrelated** to breast cancer **at some point in her lifetime?** B14.

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

9. How often does your wife/partner express concern and seek support from you about the risk of breast cancer to herself and women in her family? B49.

Never	Rarely	Sometimes	Often
1	2	3	4

10. How much of a burden is this on you? **B50.**

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

11. How often do you discuss genetic testing for breast cancer with your wife/partner? **B51.**

Never	Rarely	Sometimes	Often
1	2	3	4

12. When you have these discussions, who generally initiates them? **B52.**

You	Your Wife/partner	Equally
1	2	3

13. How satisfied are you with these discussions? **B53.**

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

14. How often do you and your wife/partner get into a disagreement or conflict over the issue of her getting genetic testing for the risk of breast cancer? **B54.**

Never	Rarely	Sometimes	Often
1	2	3	4

15. Do you think it is beneficial to have genetic testing for risk of breast cancer available to women? **B55.**

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

16. Do you want your wife/partner to get genetic testing for risk of breast cancer? **B56.**

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

22. Overall, do you feel you are adequately informed concerning your wife/partner's risk for cancer and what can be done about it? **B43a.**
- Not at All 1 2 3 4 5 6 Very Much 7
23. Do you feel you are adequately informed about the benefits and drawbacks of genetic testing for risk of breast cancer? **B44.**
- Not at All 1 2 3 4 5 6 Very Much 7
24. Do you feel you are adequately informed about what your wife/partner could do personally to reduce her risk of breast cancer if she had the altered BRCA1 gene? **B45.**
- Not at All 1 2 3 4 5 6 Very Much 7
25. Do you feel you are adequately informed about the benefits and drawbacks of options available to women who have the altered BRCA1 gene? **B46.**
- Not at All 1 2 3 4 5 6 Very Much 7
26. Do you feel you are adequately informed about what it would mean for your children if your wife/partner had the altered BRCA1 gene? ☐ **Check here if you do not have children.** **B47.**
- (-8)
- Not at All 1 2 3 4 5 6 Very Much 7
27. How confident are you that your wife/partner:
- 27a. Will make the best decision about whether to be tested for BRCA1, the altered gene associated with risk of breast cancer? **B48a.**
- Not at All 1 2 3 4 5 6 Very Much 7
- 27b. Would cope effectively with the finding that she had the altered BRCA1 gene? **B48b.**
- Not at All 1 2 3 4 5 6 Very Much 7
- 27c. Would make the best decision concerning her options if she were found to have the altered BRCA1 gene? **B48c.**
- Not at All 1 2 3 4 5 6 Very Much 7
- 27d. Would be able to follow through with her decisions and cope effectively over the long haul if she were found to have the altered BRCA1 gene? **B48d.**
- Not at All 1 2 3 4 5 6 Very Much 7

28. Please indicate the extent to which you agree or disagree with the following statements using the 1 (strongly disagree) to 5 (strongly agree) scale. Please try to provide your opinion for all of these questions. However, if you feel you simply do not know enough to have an opinion, check the "I don't know" box.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		<i>I Don't Know</i>	
a.	Mammography is effective in the early detection of breast cancer in women.	1	2	3	4	5	9	B20a.
b.	Breast cancer that is detected early is curable.	1	2	3	4	5	9	B20b.
c.	Mammography can detect lumps that cannot be felt by a woman or by her doctor.	1	2	3	4	5	9	B20c.
d.	If more women went for breast screening, there would be fewer deaths from breast cancer.	1	2	3	4	5	9	B20d.
e.	If a lump is found in a woman's breast, it is usually too late to do anything about it.	1	2	3	4	5	9	B20f.
f.	There are so many things that could happen to someone's health that it is pointless for a woman to worry about breast cancer.	1	2	3	4	5	9	B20i.
g.	If a woman were found to have breast cancer, the chances of it being cured are high.	1	2	3	4	5	9	B20m.
h.	Once a woman has had effective treatment for breast cancer, she will not get it again.	1	2	3	4	5	9	B20n.
i.	A mastectomy totally eliminates a woman's risk for breast cancer.	1	2	3	4	5	9	B20o.
j.	All women who have the altered version of the BRCA1 gene will get breast cancer.	1	2	3	4	5	9	B20p.
k.	Most of the breast cancer in the United States is due to altered versions of the BRCA1 gene.	1	2	3	4	5	9	B20q.
l.	The next decade is going to bring major advances in the detection and treatment of breast cancer.	1	2	3	4	5	9	B20r.
m.	Over the next decade, medical break-through's are going to make breast cancer much less of a threat to women's health.	1	2	3	4	5	9	B20s.

29. If your wife/partner were to take the test and find that she **did not** have the altered version of the BRCA1 gene which is associated with high risk for breast cancer, what would you expect your reactions to be?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
a.	I would feel wonderful.	1	2	3	4	5	B18a.
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	B18b.
c.	I would feel relieved.	1	2	3	4	5	B18c.
d.	I would not believe the results.	1	2	3	4	5	B18d.
e.	I would fall apart emotionally.	1	2	3	4	5	B18e.
f.	I would feel guilty.	1	2	3	4	5	B18f.
g.	I would still feel anxious.	1	2	3	4	5	B18g.
h.	I would feel angry.	1	2	3	4	5	B18h.
i.	I would feel prepared for the future.	1	2	3	4	5	B18i.
j.	I would feel I had done all I needed to do.	1	2	3	4	5	B18j.
k.	I would not feel very differently.	1	2	3	4	5	B18k.

30. If your wife/partner were to take the test and find out that she **had** the altered version of the BRCA1 gene for breast cancer, what would you expect your reactions to be?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
a.	I would feel relieved about being more certain.	1	2	3	4	5	B19a.
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	B19b.
c.	I would not believe the results.	1	2	3	4	5	B19c.
d.	I would feel guilty.	1	2	3	4	5	B19d.
e.	I would feel depressed.	1	2	3	4	5	B19e.
f.	I would feel worried about the future.	1	2	3	4	5	B19f.
g.	I would fall apart emotionally.	1	2	3	4	5	B19g.
h.	I would feel anxious.	1	2	3	4	5	B19h.
i.	I would feel angry.	1	2	3	4	5	B19i.
j.	I would not feel very differently.	1	2	3	4	5	B19j.
k.	I would want my daughters to be tested as soon as possible.	1	2	3	4	5	B19k.

31. The following questions concern your involvement in your wife/partner's health care:

		<i>Not at All</i>				<i>Very Often</i>
a.	To what extent do you go with your wife/partner to her appointments with doctors?	1	2	3	4	5
b.	To what extent do you talk with your wife/partner's doctor or other medical personnel about her risk of cancer?	1	2	3	4	5
c.	To what extent do you keep track of what your wife/partner needs to do about her risk of cancer?	1	2	3	4	5
d.	To what extent do you change your activities to look after your wife/partner?	1	2	3	4	5

H35a.

H35b.

H35c.

H35d.

32. If my wife/partner were tested and found to have the altered BRCA1 gene carrying the altered BRCA1 gene carrying increased risk of breast cancer, I would want her to manage her risk by relying on:

a. Being extra careful about breast self-examination and regular medical examinations.

B64a.

Not at All						Very Much So
1	2	3	4	5	6	7

b. Getting preventive surgery.

B64b.

Not at All						Very Much So
1	2	3	4	5	6	7

33. I do not believe it would be my place to tell my wife/partner my opinion about what she should do about her risk of breast cancer.

B65.

Strongly Disagree						Strongly Agree
1	2	3	4	5	6	7

RELATIONSHIPS

1. Is there anyone in your life with whom you can share your most private feelings without holding back? **C21.**
(1) ☐ Yes (5) ☐ No
2. Can you share your most private feelings with your wife/partner without holding back? **C21a.**
(1) ☐ Yes (5) ☐ No
3. Is there anyone besides your wife/partner with whom you can share your most private feelings without holding back? **C21b.**
(1) ☐ Yes (5) ☐ No
4. Have any of the events listed below happened to you in the past six months? **D1 (a-m)**
(Check All That Apply)
- | | |
|---|---|
| a. <input type="checkbox"/> You retired or were fired or laid off from work. | g. <input type="checkbox"/> A close family member was seriously ill or injured. |
| b. <input type="checkbox"/> You were unemployed and looking for work. | h. <input type="checkbox"/> You had a marital separation or divorce. |
| c. <input type="checkbox"/> Your spouse retired or was fired or laid off from work. | i. <input type="checkbox"/> You had serious troubles with relatives or close friends. |
| d. <input type="checkbox"/> Your spouse was unemployed and looking for work. | j. <input type="checkbox"/> Your spouse had troubles with relatives or close friends. |
| e. <input type="checkbox"/> You had problems with the police or court. | k. <input type="checkbox"/> A close family member died. |
| f. <input type="checkbox"/> You got into serious financial difficulties. | l. <input type="checkbox"/> A close friend or relative died. |
| | m. <input type="checkbox"/> You were seriously ill or injured. |

MARRIAGE SECTION

Most people have disagreements in their relationships. Please indicate, using check marks the extent of agreement or disagreement experienced between you and your wife/partner on the following issues **DURING THE PAST MONTH.**

		<i>Always Agree</i>	<i>Almost Always Agree</i>	<i>Occa- sionally Disagree</i>	<i>Fre- quently Disagree</i>	<i>Almost Always Disagree</i>	<i>Always Disagree</i>	
1.	Handling family finances	1	2	3	4	5	6	H1.
2.	Matters of recreation	1	2	3	4	5	6	H2.
3.	Religious matters	1	2	3	4	5	6	H3.
4.	Demonstration of affection	1	2	3	4	5	6	H4.
5.	Friends	1	2	3	4	5	6	H5.
6.	Sex relations	1	2	3	4	5	6	H6.
7.	Conventionality (correct or proper behavior)	1	2	3	4	5	6	H7.
8.	Philosophy of life	1	2	3	4	5	6	H8.
9.	Ways of dealing with parents or in-laws	1	2	3	4	5	6	H9.
10.	Aims, goals, and things believed important	1	2	3	4	5	6	H10.
11.	Amount of time spent together	1	2	3	4	5	6	H11.
12.	Making major decisions	1	2	3	4	5	6	H12.
13.	Household tasks	1	2	3	4	5	6	H13.
14.	Leisure time interests and activities	1	2	3	4	5	6	H14.
15.	Career decisions	1	2	3	4	5	6	H15.

		<i>All of the Time</i>	<i>Most of the Time</i>	<i>More Often than Most</i>	<i>Occa- sionally</i>	<i>Rarely</i>	<i>Never</i>	
16.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6	H16.
17.	How often do you or your wife/partner leave the house after a fight?	1	2	3	4	5	6	H17.
18.	In general, how often do you think that things between you and your wife/partner are going well?	1	2	3	4	5	6	H18.
19.	Do you confide in your wife/partner?	1	2	3	4	5	6	H19.
20.	Do you ever regret that you married (or lived together)?	1	2	3	4	5	6	H20.
21.	How often do you and your wife/partner quarrel?	1	2	3	4	5	6	H21.
22.	How often do you and your wife/partner "get on each other's nerves?"	1	2	3	4	5	6	H22.

		<i>Every Day</i>	<i>Almost Every Day</i>	<i>Occa- sionally</i>	<i>Rarely</i>	<i>Never</i>	
23.	Do you kiss your wife/partner?	1	2	3	4	5	H23.

		<i>All of Them</i>	<i>Most of Them</i>	<i>Some of Them</i>	<i>Very few of Them</i>	<i>None of Them</i>	
24.	Do you and your wife/partner engage in outside interests together?	1	2	3	4	5	H24.

How often would you say the following events occur between you and your wife/partner?

		Never	Less than once a month	About twice a month	About twice a week	Once a day	More Often
25.	Have a stimulating exchange of ideas	1	2	3	4	5	6
26.	Laugh together	1	2	3	4	5	6
27.	Calmly discuss something	1	2	3	4	5	6
28.	Work together on a project	1	2	3	4	5	6

H25.

H26.

H27.

H28.

These are some things couples sometimes agree and sometimes disagree upon. Indicate if either item below caused differences of opinions or were problems in your relationship during the past month. **(Check yes or no).**

29. Being too tired for sex. (1) ☐ Yes (5) ☐ No

H29.

30. Not showing love. (1) ☐ Yes (5) ☐ No

H30.

31. The following scale represents different degrees of happiness in your relationship. The middle point "happy" represents the degree of happiness of most relationships. Please circle the number which best describes the degree of happiness, all things considered, of your relationship.

H31.

Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect
1	2	3	4	5	6	7

32. Please check one of the following statements to best describe how you feel about the **future** of your relationship.

H32.

- (1).___ I want desperately for my relationship to succeed, and would go to almost any length to see that it does.
- (2).___ I want very much for my relationship to succeed, and will do all I can to see that it does.
- (3).___ I want very much for my relationship to succeed, and will do my fair share to see that it does.
- (4).___ It would be very nice if my relationship succeeded, but I can't do much more than I am doing now to help it succeed.
- (5).___ It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.
- (6).___ My relationship can never succeed, and there is no more that I can do to keep the relationship going.

33. Considering **only the positive feelings** you have toward your wife/partner, and **ignoring the negative ones**, please rate how positive these feelings are: H33.

Not At All Positive					Extremely Positive				
1	2	3	4	5	6	7	8	9	10

34. Considering **only the negative feelings** you have toward your wife/partner, and **ignoring the positive ones**, please rate how negative these feelings are: H34.

Not At All Negative					Extremely Negative				
1	2	3	4	5	6	7	8	9	10

CURRENT FAMILY SECTION

Please indicate the extent to which each of the following items describes your current family (your household).

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
1.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5	M1.
2.	In times of crisis we can turn to each other for support.	1	2	3	4	5	M2.
3.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5	M3.
4.	Individuals are accepted for who they are.	1	2	3	4	5	M4.
5.	We avoid discussing our fears and concerns.	1	2	3	4	5	M5.
6.	We can express feelings to each other.	1	2	3	4	5	M6.
7.	There are lots of bad feelings in the family.	1	2	3	4	5	M7.
8.	We feel accepted for who we are.	1	2	3	4	5	M8.
9.	Making decisions is a problem for our family.	1	2	3	4	5	M9.
10.	We are able to make decisions about how to solve problems.	1	2	3	4	5	M10.
11.	We don't get along well together.	1	2	3	4	5	M11.
12.	We confide in each other.	1	2	3	4	5	M12.

YOUR HEALTH AND MOOD SECTION

1. In general, would you say your health is: I1.
- (1) ☐ Excellent (2) ☐ Very Good (3) ☐ Good (4) ☐ Fair (5) ☐ Poor
2. Have you **ever in your life** had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I14.
- (1) ☐ Yes (5) ☐ No (Skip to Question 3)
- 2a. If there was such a two-week period, did your work or relationships suffer? I14a.
- (1) ☐ Yes (5) ☐ No
- 2b. If there was such a two-week period, did you get counseling or psychotherapy? I14b.
- (1) ☐ Yes (5) ☐ No
- 2c. If there was such a two-week period, did you get medication for this condition? I14c.
- (1) ☐ Yes (5) ☐ No
3. In the **past 6 months**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I12.
- (1) ☐ Yes (5) ☐ No (Skip to Question 4)
- 3a. If there was such a two-week period (**in the past 6 months**), did your work or relationships suffer? I12a.
- (1) ☐ Yes (5) ☐ No
- 3b. If there was such a two-week period (**in the past 6 months**), did you get counseling or psychotherapy? I12b.
- (1) ☐ Yes (5) ☐ No
- 3c. If there was such a two-week period, (**in the past 6 months**) did you get medication for this problem? I12c.
- (1) ☐ Yes (5) ☐ No
4. Are you **currently** receiving counseling, psychotherapy, or medication for depression or emotional problems? I13.
- (1) ☐ Yes (5) ☐ No

SYMPTOMS OF STRAIN SECTION

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the **Past Three Months**.*

		<i>1</i> <i>Not at all</i>	<i>2</i> <i>A little</i>	<i>3</i> <i>Quite a bit</i>	<i>4</i> <i>Extremely</i>	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energy--slowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

COPING SECTION

1. Imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do? Please answer **yes** or **no** for each choice.

		YES	NO	
a.	I would ask the dentist exactly what s/he was going to do.	1	5	L1_1
b.	I would take a tranquilizer or have a drink before going.	1	5	L1_2
c.	I would try to think about pleasant memories.	1	5	L1_3
d.	I would want the dentist to tell me when I would feel pain.	1	5	L1_4
e.	I would try to sleep.	1	5	L1_5
f.	I would watch all the dentist's movements and listen for the sound of the drill.	1	5	L1_6
g.	I would watch the flow of water from my mouth to see if it contained blood.	1	5	L1_7
h.	I would do mental puzzles in my mind.	1	5	L1_8

2. Imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do?

		YES	NO	
a.	I would sit by myself and have as many daydreams and fantasies as I could.	1	5	L2_1
b.	I would stay alert and try to keep myself from falling asleep.	1	5	L2_2
c.	I would exchange life stories with the other hostages.	1	5	L2_3
d.	If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing.	1	5	L2_4
e.	I would watch every movement of my captors and keep an eye on their weapons.	1	5	L2_5
f.	I would try to sleep as much as possible.	1	5	L2_6
g.	I would think about how nice it's going to be when I get home.	1	5	L2_7
h.	I would make sure I knew where every possible exit was.	1	5	L2_8

3. Imagine that due to a large drop in sales, it is rumored that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about lay-off has been made and will be announced in several days. Please answer **yes** or **no** for each choice.

		YES	NO	
a.	I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said.	1	5	L3_1
b.	I would review the list of duties for my present job and try to figure out if I had fulfilled them all.	1	5	L3_2
c.	I would go to the movies to take my mind off things.	1	5	L3_3
d.	I would try to remember any arguments or disagreements I might have had with the supervisor that would have lowered his opinion of me.	1	5	L3_4
e.	I would push all thoughts of being laid off out of my mind.	1	5	L3_5
f.	I would tell my spouse that I'd rather not discuss my chances of being laid off.	1	5	L3_6
g.	I would try to think which employees in my department the supervisor might have thought had done the worst job.	1	5	L3_7
h.	I would continue doing my work as if nothing special was happening.	1	5	L3_8

4. Imagine that you are on an airplane, 30 minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced that all is well. Please answer **yes** or **no** for each choice.

		YES	NO	
a.	I would carefully read the information provided about safety features in the plane and make sure I knew where the emergency exits were.	1	5	L4_1
b.	I would make small talk with the passenger beside me.	1	5	L4_2
c.	I would watch the end of the movie, even if I had seen it before.	1	5	L4_3
d.	I would call for the flight attendant and ask her/him exactly what the problem was.	1	5	L4_4
e.	I would order a drink or tranquilizer from the stewardess.	1	5	L4_5
f.	I would listen carefully to the engines for unusual noises and would watch the crew to see if their behavior was out of the ordinary.	1	5	L4_6
g.	I would talk to the passenger beside me about what might be wrong.	1	5	L4_7
h.	I would settle down and read a book or magazine or write a letter.	1	5	L4_8

5. This set of questions deals with ways you've been coping with the stress in your life that goes with your wife/partner possibly having the altered BRCA1 gene associated with risk for breast cancer. Obviously, different people deal with this stress in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know *to what extent* you've been doing what the item says, how *much* or how *frequently*. Don't answer on the basis of whether it seems to be working, but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>	
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4	L7_a.
b.	I've been concentrating my efforts on doing something about her situation.	1	2	3	4	L7_b.
c.	I've been saying to myself "this isn't possible."	1	2	3	4	L7_c.
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4	L7_d.
e.	I've been getting emotional support from others.	1	2	3	4	L7_e.
f.	I've been giving up trying to deal with it.	1	2	3	4	L7_f.
g.	I've been taking action to try to make the situation better.	1	2	3	4	L7_g.
h.	I've been refusing to believe that it is possible she has the gene.	1	2	3	4	L7_h.
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	L7_i.
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	L7_j.
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4	L7_k.
l.	I've been trying to come up with a strategy for what to do.	1	2	3	4	L7_l.
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7_m.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>	
n.	I've been giving up the attempt to cope.	1	2	3	4	L7_n.
o.	I've been accepting the possibility that she might have the gene.	1	2	3	4	L7_o.
p.	I've been expressing my negative feelings.	1	2	3	4	L7_p.
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4	L7_q.
r.	I've been learning to live with the possibility she might have the gene.	1	2	3	4	L7_r.
s.	I've been thinking hard about what steps to take.	1	2	3	4	L7_s.
t.	I've been praying or meditating.	1	2	3	4	L7_t.
u.	I've been making fun of the situation.	1	2	3	4	L7_u.
v.	I've been giving pep talks and encouraging my wife/partner.	1	2	3	4	L7_v.
w.	I've been denying or hiding my anger around my wife/partner.	1	2	3	4	L7_w.
x.	I've been denying or hiding my own worries around my wife/partner.	1	2	3	4	L7_x.
y.	I've been trying to give my wife/partner opportunities to talk about her worries.	1	2	3	4	L7_y.
z.	I've been trying to find out what my wife/partner is feeling.	1	2	3	4	L7_z.
aa.	I've been avoiding talking about my own problems around my wife/partner.	1	2	3	4	L7_aa.
bb.	I've acted more positive around my wife/partner than I feel.	1	2	3	4	L7_bb.

6. For each of the statements on the following page, indicate the degree to which this change occurred in your life as a result of your wife/partner possibly having an altered gene associated with greater risk for breast cancer. Please use the following scale:

- 1 = I experienced **no change** as a result of my wife/partner possibly having an altered gene associated with greater risk for breast cancer.
- 2 = I experienced this change to a **very small degree** as a result of my wife/partner possibly having an altered gene associated with greater risk for breast cancer.
- 3 = I experienced this change to a **small degree** as a result of my wife/partner possibly having an altered gene associated with greater risk for breast cancer.
- 4 = I experienced this change to a **moderate degree** as a result of my wife/partner possibly having an altered gene associated with greater risk for breast cancer.
- 5 = I experienced this change to a **great degree** as a result of my wife/partner possibly having an altered gene associated with greater risk for breast cancer.
- 6 = I experienced this change to a **very great degree** as a result of my wife/partner possibly having an altered gene associated with greater risk for breast cancer.

		No Change	Very Small Degree	Small Degree	Moderate Degree	Great Degree	Very Great Degree	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6_a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6_b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6_c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6_d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6_e.
f.	Knowing that I can count on people in times of trouble.	1	2	3	4	5	6	L6_f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6_g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6_h.
i.	A willingness to express my emotions.	1	2	3	4	5	6	L6_i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6_j.
k.	Appreciating each day.	1	2	3	4	5	6	L6_k.
l.	Having compassion for others.	1	2	3	4	5	6	L6_l.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6_m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6_n.

Thank you for your valued participation in this study.

☐ ☐ ☐ ☐ - ☐



WOMEN'S HEALTH STUDY

Pre-Results Questionnaire

ID _____

This questionnaire, from the Women's Health Study being conducted by the University of Michigan Medical Center and the University of Pennsylvania Cancer Center, is being given to women who are now being offered the opportunity to learn whether they have the altered gene associated with risk for early breast cancer. Again, we remind you that many of the questions are new. Some of them were asked in the first questionnaire you completed. We are asking them again because we are interested in feelings and attitudes which may change over time. **THANK YOU VERY MUCH!**

1. Have you met with anyone to have genetic counseling? B24.

1 5

☐ Yes ☐ No

2. Has any member of your family met with someone to have genetic counseling ? **B25.**
- 1 5
- ☐ Yes ☐ No

3. Do you believe you have the altered gene that increases the risk of breast cancer? **B72.**
- 1 5
- ☐ Yes ☐ No

4. How confident are you in this belief?

Not At All Confident						Very Confident	
1	2	3	4	5	6	7	

5. As the opportunity to get testing has approached, has your interest in getting results changed? B74.

Decreased Very Much	Decreased Slightly	No Change	Increased Slightly	Increased Very Much
1	2	3	4	5

PERSONAL ATTITUDES SECTION

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
a.	If you don't have your health, you don't have anything.	1	2	3	4	5	L5a.
b.	There are many things I care about more than my health.	1	2	3	4	5	L5b.
c.	Good health is of only minor importance in a happy life.	1	2	3	4	5	L5c.
d.	There is nothing more important than good health.	1	2	3	4	5	L5d.
e.	In uncertain times, I usually expect the best.	1	2	3	4	5	E1.
f.	It's easy for me to relax.	1	2	3	4	5	E2.
g.	If something can go wrong for me, it will.	1	2	3	4	5	E3.
h.	I always look on the bright side of things.	1	2	3	4	5	E4.
i.	I'm always optimistic about my future.	1	2	3	4	5	E5.
j.	I enjoy my friends a lot.	1	2	3	4	5	E6.
k.	It's important for me to keep busy.	1	2	3	4	5	E7.
l.	I hardly ever expect things to go my way.	1	2	3	4	5	E8.
m.	Things never work out the way I want them to.	1	2	3	4	5	E9.
n.	I don't get upset too easily.	1	2	3	4	5	E10.
o.	I'm a believer in the idea that "every cloud has a silver lining."	1	2	3	4	5	E11.
p.	I rarely count on good things happening to me.	1	2	3	4	5	E12.

GENETIC TESTING-SECTION 2

1. Even though you have been diagnosed with breast cancer, would you consider taking the genetic test to learn if your cancer is the type that runs in families?

(Please check one response).

B15.

- a. _____ I will definitely take the test immediately when it becomes available.
 b. _____ I will definitely take the test, but I am not sure if immediately.
 c. _____ I will probably take the test immediately when it becomes available.
 d. _____ I will probably take the test, but not immediately.
 e. _____ I am undecided whether I will take the test
 f. _____ I will probably not take the test.
 g. _____ I will definitely not take the test.

2. On the following scale, indicate how distressing it is for you to know that you may be at increased risk for recurrence breast cancer because of your family history?

B66.

Not At All Distressing		Very Distressing		
1	2	3	4	5

3. How distressing it is to be given the opportunity to be tested for the BRCA-1 gene, the altered gene associated with increased risk for breast cancer?

B67.

Not At All Distressing		Very Distressing		
1	2	3	4	5

4. How distressed do you expect to be when you actually get tested for the BRCA-1 gene (before you receive results)?

B68.

Not At All Distressed		Very Distressed		
1	2	3	4	5

5. How distressed would you be if you took the test and found that you **had** the BRCA-1 gene?

B69.

Not At All Distressed		Very Distressed		
1	2	3	4	5

6. How distressed would you be if you took the test and found that you **did not have** the BRCA-1 gene? **B70.**

Not At All Distressed				Very Distressed
1	2	3	4	5

7. Overall, to what extent do you welcome the opportunity to be tested for the BRCA-1 gene? **B71.**

Not At All				Very Much So
1	2	3	4	5

		Not At All					All The Time
8.	How often do you worry about again developing breast cancer?	1	2	3	4	5	B27.
9.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B28.
10.	How often do you worry about having the altered gene carrying risk for breast cancer ?	1	2	3	4	5	B29.
11.	To what extent do these worries you have about having this altered gene interfere with your every day life?	1	2	3	4	5	B30.

12. Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to other women? **(Please circle one)** **B7.**

Much Less Likely			Much More Likely	
1	2	3	4	5

13. When was the last time you had a mammography? **B32.**
 _____Month _____Year ⁽⁹⁹⁾ ☐ This question does not apply because of surgery.

14. How many times have you conducted a breast self-examinations (BSE) in the past six months? **B33.**

_____times ⁽⁹⁹⁾ ☐ This question does not apply because of surgery.

15. How confident are you that you will perform breast self examination (BSE) ---

15a. --as **frequently** as needed? (9) ☐ Does Not Apply Because of Surgery **B34a.**

Not at All 1 2 3 4 5 6 7 Very Much So

15b. --as **carefully and competently** as needed? **B34b.**
(9) ☐ Does Not Apply Because of Surgery

Not at All 1 2 3 4 5 6 7 Very Much So

For each of the following areas of your life, you will be asked to make **two** ratings. First, indicate how much these decisions have been affected by the possibility that you have an increased risk for breast cancer (based on your family history). Second, how much would these decisions be affected by the results of genetic testing?

1	2	3	4	5
Not at all affected				Very much affected

		<u>Have been affected by being at increased risk for breast cancer</u>					<u>Would be affected by the results of genetic testing</u>					
		1	2	3	4	5	1	2	3	4	5	
16.	Decisions about having children											B35a B35b
17.	Decisions about form of birth control											B36a B36b
18.	Decisions about which steps to take to prevent the recurrence of breast cancer											B37a B37b
19.	Decisions about work and career											B38a B38b
20.	Decisions about savings and financial planning											B39a B39b
21.	Decisions about plans for the future											B40a B40b

22. **Answer the following question only if you have daughters.**

☐ Does Not Apply
(Skip to Next Section, Life Events)

B41.

		<u>Have been affected by being at high risk for breast cancer</u>					<u>Would be affected by the results of genetic testing</u>					
a.	Plans for your daughter's future	1	2	3	4	5	1	2	3	4	5	B42a B42b

LIFE EVENTS SECTION

1. **Have any of the following events happened to you in the past six months?**
(Check All That Apply)

D1(a-m)

- | | |
|---|---|
| <p>a. <input type="checkbox"/> You retired, were fired, or laid off from work.</p> <p>b. <input type="checkbox"/> You were unemployed and looking for work.</p> <p>c. <input type="checkbox"/> Your spouse retired, was fired, or laid off from work.</p> <p>d. <input type="checkbox"/> Your spouse was unemployed and looking for work.</p> <p>e. <input type="checkbox"/> You had problems with the police or court.</p> <p>f. <input type="checkbox"/> You got into serious financial difficulties.</p> | <p>g. <input type="checkbox"/> A close family member was seriously ill or injured.</p> <p>h. <input type="checkbox"/> You had a marital separation or divorce.</p> <p>i. <input type="checkbox"/> You had serious troubles with relatives or close friends.</p> <p>j. <input type="checkbox"/> Your spouse had troubles or difficulties with relatives or close friends.</p> <p>k. <input type="checkbox"/> A close family member died.</p> <p>l. <input type="checkbox"/> A close friend or relative died.</p> <p>m. <input type="checkbox"/> You were seriously ill or injured.</p> |
|---|---|

MARRIAGE SECTION

The following questions apply to persons who are married or living with a partner. If you are not married or living with a partner, check the appropriate box and please skip to the Next Section, MOOD.

Not married or living with a partner ☐

Ha.

Most persons have disagreements in their relationships. Please check the appropriate box to indicate the extent of agreement or disagreement experienced between you and your partner **DURING THE PAST MONTH**, regarding.

		6	5	4	3	2	1	
		<i>Always Agree</i>	<i>Almost Always Agree</i>	<i>Occasionally Disagree</i>	<i>Frequently Disagree</i>	<i>Almost Always Disagree</i>	<i>Always Disagree</i>	
1.	Religious matters							H3.
2.	Demonstration of affection							H4.
3.	Sex relations							H6.
4.	Conventionality (correct or proper behavior)							H7.
5.	Making major decisions							H12.
6.	Career decisions							H15.

		1	2	3	4	5	6	
		<i>All of the time</i>	<i>Most of the time</i>	<i>More often than most</i>	<i>Occasionally</i>	<i>Rarely</i>	<i>Never</i>	
7.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?							H16.
8.	Do you ever regret that you married (or are living together)?							H20.
9.	How often do you and your husband/partner quarrel?							H21.
10.	How often do you and your husband/partner "get on each other's nerves?"							H22.

		5	4	3	2	1
		<i>All of Them</i>	<i>Most of Them</i>	<i>Some of Them</i>	<i>Very few of Them</i>	<i>None of Them</i>
11.	Do you and your husband/partner engage in outside interests together?					

H24.

How often would you say the following events occur between you and your husband/partner?

		1	2	3	4	5	6
		<i>Never</i>	<i>Less than once a month</i>	<i>About twice a month</i>	<i>About twice a week</i>	<i>Once a day</i>	<i>More Often</i>
12.	Have a stimulating exchange of ideas						
13.	Calmly discuss something						
14.	Work together on a project						

H25.

H27.

H28.

15. Considering **only the positive feelings** you have toward your husband/partner, and **ignoring the negative ones**, please rate how positive these feelings are:

H33.

Not At All Positive					Extremely Positive				
1	2	3	4	5	6	7	8	9	10

16. Considering **only the negative feelings** you have toward your husband/partner, and **ignoring the positive ones**, please rate how negative these feelings are:

H34.

Not At All Negative					Extremely Negative				
1	2	3	4	5	6	7	8	9	10

17. The following questions concern your husband's involvement in your health care.

		Never Very Often					
a.	How often does your husband/partner go with you to your appointments with doctors?	1	2	3	4	5	H35a.
b.	How often does your husband/partner talk with your doctor or other medical personnel about your risk for breast cancer?	1	2	3	4	5	H35b.
c.	How often does your husband/partner keep track of what you need to do about your risk for breast cancer?	1	2	3	4	5	H35c.
d.	How often does your husband/partner change his activities to assist you in your health care?	1	2	3	4	5	H35d.

18. Has your husband/partner attended individual, family or group sessions to become informed about your risk for breast cancer and what can be done? H36.

(1) Yes ☐ (5) No ☐

19. How much contact has your husband/partner had with medical personnel concerning your risk for breast cancer. H37.

Very Little
or None
1 2 3 4 5 6 A lot
7

20. Do you feel your husband/partner is adequately informed concerning your risk for breast cancer and what can be done about it? H38.

Not at All Very Much
1 2 3 4 5 6 7

21. To what extent are you satisfied with your husband/partner's involvement in your health care? H39.

Not at All Very Much
1 2 3 4 5 6 7

MOOD SECTION

1. Have you **ever in your lifetime** had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? **I14**
- (1) ☐ Yes (5) ☐ No
- 1a. If **yes**, there was such a two-week period, did your work or relationships suffer? **I14a.**
- (1) ☐ Yes (5) ☐ No
- 1b. If **yes**, there was such a two-week period, did you get counseling or psychotherapy? **I14b.**
- (1) ☐ Yes (5) ☐ No
- 1c. If **yes**, there was such a two-week period, did you get medication for this condition? **I14c.**
- (1) ☐ Yes (5) ☐ No
2. In the **past 6 months**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? **I12.**
- (1) ☐ Yes (5) ☐ No
- 2a. If **yes**, there was such a two-week period in **the past 6 months**, did your work or relationships suffer? **I12a.**
- (1) ☐ Yes (5) ☐ No
- 2b. If **yes**, there was such a two-week period in **the past 6 months**, did you get counseling or psychotherapy? **I12b.**
- (1) ☐ Yes (5) ☐ No
- 2c. If **yes**, there was such a two-week period in **the past 6 months**, did you get medication for this condition? **I12c.**
- (1) ☐ Yes (5) ☐ No
3. Are you **currently** receiving counseling, psychotherapy or medication for depression or emotional problems? **I13.**
- (1) ☐ Yes (5) ☐ No

STRAIN SECTION

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the **Past Three Months.***

		<u>1</u> <u>Not at all</u>	<u>2</u> <u>A little</u>	<u>3</u> <u>Quite a bit</u>	<u>4</u> <u>Extremely</u>	
1.	Suddenly scared for no reason					K1.
2.	Feeling fearful					K2.
3.	Faintness, dizziness, or weakness					K3.
4.	Nervousness or shakiness inside					K4.
5.	Heart pounding or racing					K5.
6.	Trembling					K6.
7.	Feeling tense or keyed up					K7.
8.	Headaches					K8.
9.	Spells of terror or panic					K9.
10.	Feeling restless, can't sit still					K10.
11.	Feeling low in energy--slowed down					K11.
12.	Blaming yourself for things					K12.
13.	Crying easily					K13.
14.	Loss of sexual interest or pleasure					K14.
15.	Poor appetite					K15.
16.	Difficulty falling asleep, staying asleep					K16.
17.	Feeling hopeless about the future					K17.
18.	Feeling blue					K18.
19.	Feeling lonely					K19.
20.	Feeling trapped or caught					K20.
21.	Worrying too much about things					K21.
22.	Feeling no interest in things					K22.
23.	Thoughts of ending your life					K23.
24.	Feeling everything is an effort					K24.
25.	Feelings of worthlessness					K25.

COPING SECTION

1. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of your risk for breast cancer. For each of the statements below, indicate the degree to which your life is affected positively by your risk of breast cancer.

		<i>Not At All</i>	<i>A Very Small Degree</i>	<i>A Small Degree</i>	<i>A Moderate Degree</i>	<i>A Great Degree</i>	<i>A Very Great Degree</i>	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e.
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h.
i.	A willingness to express my emotions.	1	2	3	4	5	6	L6i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6j.
k.	Appreciating each day.	1	2	3	4	5	6	L6k.
l.	Having compassion for others.	1	2	3	4	5	6	L6l.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n.

2. This set of questions deals with ways you've been coping with the stress in your life that comes with being at risk for breast cancer. There are many ways people try to deal with problems. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know *to what extent* you've been doing what the item says, how *much* or how *frequently*. Don't answer on the basis of whether it seems to be working but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		<i>I haven't been doing this at all</i> 1	<i>I've been doing this a little bit</i> 2	<i>I've been doing this some</i> 3	<i>I've been doing this a lot</i> 4	
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4	L7a.
b.	I've been concentrating my efforts on doing something about my situation.	1	2	3	4	L7b.
c.	I've been saying to myself "this isn't possible."	1	2	3	4	L7c.
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4	L7d.
e.	I've been getting emotional support from others.	1	2	3	4	L7e.
f.	I've been giving up trying to deal with it.	1	2	3	4	L7f.
g.	I've been taking action to try to make the situation better.	1	2	3	4	L7g.
h.	I've been refusing to believe that it is possible that I have the gene.	1	2	3	4	L7h.
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	L7i.
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	L7j.
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4	L7k.
l.	I've been trying to come up with a strategy about what to do.	1	2	3	4	L7l.
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7m.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>
n.	I've been giving up the attempt to cope.	1	2	3	4
o.	I've been accepting the possibility that I might have the gene.	1	2	3	4
p.	I've been expressing my negative feelings.	1	2	3	4
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
r.	I've been learning to live with the possibility that I might have the gene.	1	2	3	4
s.	I've been thinking hard about what steps to take.	1	2	3	4
t.	I've been praying or meditating.	1	2	3	4
u.	I've been making fun of the situation.	1	2	3	4

L7n.

L7o.

L7p.

L7q.

L7r.

L7s.

L7t.

L7u.

3. The following items are to be answered only by those women who are married or living with a partner.

☐ Not married or living with a partner

L8.

(Skip to Last Section on page 15, Background Data)

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>
a.	I've been denying or hiding my anger around my husband/partner.	1	2	3	4
b.	I've been denying or hiding my worries around my husband/partner.	1	2	3	4
c.	I've been avoiding talking about my problems around my husband/partner.	1	2	3	4
d.	I've acted more positive around my husband/partner than I feel.	1	2	3	4

L8a.

L8b.

L8c.

L8d.

BACKGROUND DATA

These are a few questions about your religious background, that we forgot to ask on the original questionnaire.

1. Religion: Catholic (1) ☐ Protestant (4) ☐ A 3.
Jewish (2) ☐ Buddhist (5) ☐
Muslim (3) ☐ Other (6) ☐
None (7) ☐

- 1a. How often do you attend religious services? A 3 a.
(1) (5)
☐ Less Often Than Once a Month ☐ A Few Times A Month or More

- 1b. How important are religious and spiritual beliefs in your life? A 3 b.
Not at All Very Important
1 2 3 4 5

Once Again, We thank you for all of your valued participation in this study.

☐ ☐ ☐ ☐ - ☐



WOMEN'S HEALTH STUDY

Pre-Results Questionnaire

ID _____

This questionnaire, from the Women's Health Study being conducted by the University of Michigan Medical Center and the University of Pennsylvania Cancer Center, is being given to women who are now being offered the opportunity to learn whether have the altered gene associated with risk for early breast cancer. Again, we remind you that many of the questions are new. Some of them were asked in the first questionnaire you completed. We are asking them again because we are interested in feelings and attitudes which may change over time. **THANK YOU VERY MUCH!**

1. Have you met with anyone to have genetic counseling? B24.

1 5

☐ Yes ☐ No

2. Has any member of your family met with someone to have genetic counseling? **B25.**
- 1 5
☐ Yes ☐ No

3. Do you believe you have the altered gene that increases the risk of breast cancer? **B72.**
 1 5
☐ Yes ☐ No

- | Not At All
Confident | | | | | | Very
Confident |
|-------------------------|---|---|---|---|---|-------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |

5. As the opportunity to get testing has approached, has your interest in getting results changed? B74.

Decreased Very Much	Decreased Slightly	No Change	Increased Slightly	Increased Very Much
1	2	3	4	5

PERSONAL ATTITUDES SECTION

1. For each of these statements, please indicate the extent to which you agree or disagree by circling the appropriate number. There are no right or wrong answers. We are only interested in your opinions.

		<i>Strongly Disagree</i>		<i>Strongly Agree</i>			
		1	2	3	4	5	
a.	If you don't have your health, you don't have anything.						L5a.
b.	There are many things I care about more than my health.						L5b.
c.	Good health is of only minor importance in a happy life.						L5c.
d.	There is nothing more important than good health.						L5d.
e.	In uncertain times, I usually expect the best.						E1.
f.	It's easy for me to relax.						E2.
g.	If something can go wrong for me, it will.						E3.
h.	I always look on the bright side of things.						E4.
i.	I'm always optimistic about my future.						E5.
j.	I enjoy my friends a lot.						E6.
k.	It's important for me to keep busy.						E7.
l.	I hardly ever expect things to go my way.						E8.
m.	Things never work out the way I want them to.						E9.
n.	I don't get upset too easily.						E10.
o.	I'm a believer in the idea that "every cloud has a silver lining."						E11.
p.	I rarely count on good things happening to me.						E12.

GENETIC TESTING-SECTION 2

1. Are you planning to take the genetic test to learn if your cancer is the type that runs in families?
(Please check one response). B15.

- a. _____ I will definitely take the test immediately when it becomes available.
 b. _____ I will definitely take the test, but I am not sure if immediately.
 c. _____ I will probably take the test immediately when it becomes available.
 d. _____ I will probably take the test, but not immediately.
 e. _____ I am undecided whether I will take the test
 f. _____ I will probably not take the test.
 g. _____ I will definitely not take the test.

2. On the following scale, indicate how distressing it is for you to know that you may be at increased risk for breast cancer because of your family history? B66.

Not At All Distressing		Very Distressing		
1	2	3	4	5

3. How distressing it is to be given the opportunity to be tested for the BRCA-1 gene, the altered gene associated with increased risk for breast cancer? B67.

Not At All Distressing		Very Distressing		
1	2	3	4	5

4. How distressed do you expect to be when you actually get tested for the BRCA-1 gene (just before you receive results)? B68.

Not At All Distressed		Very Distressed		
1	2	3	4	5

5. How distressed would you be if you took the test and found that you **had** the BRCA-1 gene? B69.

Not At All Distressed		Very Distressed		
1	2	3	4	5

6. How distressed would you be if you took the test and found that you **did not have** the BRCA-1 gene? **B70.**

Not At All Distressed				Very Distressed
1	2	3	4	5

7. Overall, to what extent do you welcome the opportunity to be tested for the BRCA-1 gene? **B71.**

Not At All				Very Much So
1	2	3	4	5

		Not At All					All The Time		
8.	How often do you worry about developing breast cancer?	1	2	3	4	5			B27.
9.	To what extent do these worries interfere with your every day life?	1	2	3	4	5			B28.
10.	How often do you worry about having the altered gene carrying risk for breast cancer ?	1	2	3	4	5			B29.
11.	To what extent do these worries you have about having this altered gene interfere with your every day life?	1	2	3	4	5			B30.

12. When was the last time you had a mammography? **B32.**

(99)
 _____Month _____Year ☐ This question does not apply because of surgery.

13. How many times have you conducted a breast self-examinations (BSE) in the past six months? **B33.**

_____times (99) ☐ This question does not apply because of surgery.

14. How confident are you that you will perform breast self examination (BSE) ---

14a. --as **frequently** as needed? (9) ☐ Does Not Apply Because of Surgery **B34a.**

Not at All Very Much So
1 2 3 4 5 6 7

14b. --as **carefully and competently** as needed? **B34b.**
(9) ☐ Does Not Apply Because of Surgery

Not at All Very Much So
1 2 3 4 5 6 7

For each of the following areas of your life, you will be asked to make **two** ratings. First, indicate how much these decisions have been affected by the possibility that you have an increased risk for breast cancer (based on your family history). Second, how much would these decisions be affected by the results of genetic testing?

1	2	3	4	5
Not at all affected				Very much affected

		<u>Have been affected by being at risk for breast cancer</u>					<u>Would be affected by the results of genetic testing</u>					
15.	Decisions about having children	1	2	3	4	5	1	2	3	4	5	B35a B35b
16.	Decisions about form of birth control	1	2	3	4	5	1	2	3	4	5	B36a B36b
17.	Decisions about which steps to take to prevent the recurrence of breast cancer	1	2	3	4	5	1	2	3	4	5	B37a B37b
18.	Decisions about work and career	1	2	3	4	5	1	2	3	4	5	B38a B38b
19.	Decisions about savings and financial planning	1	2	3	4	5	1	2	3	4	5	B39a B39b
20.	Decisions about plans for the future	1	2	3	4	5	1	2	3	4	5	B40a B40b

21. Answer the following question only if you have daughters.

☐ Does Not Apply
(Skip to Next Section, Life Events)

B41.

		<u>Have been affected by being at high risk for breast cancer</u>					<u>Would be affected by the results of genetic testing</u>					B42 a/b
a-b.	Plans for your daughter's future	1	2	3	4	5	1	2	3	4	5	

22. Do you feel you have enough information about breast cancer to make any decisions that might be necessary?

Not At All						Very Much
1	2	3	4	5	6	7

B43.

23. Do you feel you are adequately informed about the benefits and drawbacks of genetic testing for risk of breast cancer?

Not At All						Very Much
1	2	3	4	5	6	7

B44.

24. Do you feel you are adequately informed about what you could do to reduce your risk of breast cancer if you had the altered BRCA1 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B45.

25. Do you feel you are adequately informed about the benefits and drawbacks of each option available to women who have the altered BRCA1 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B46.

26. Do you feel you are adequately informed about what it would mean for your children if you had the altered BRCA1 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B47.

27. How confident are you that you:

- a. Will make the best decision in deciding whether to be tested for BRCA1, the altered gene associated with risk of breast cancer?

Not At All						Very Much
1	2	3	4	5	6	7

B48a.

- b. Would cope effectively with a finding that you had the altered BRCA1 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B48b.

- c. Would make the best decision concerning your options if you were found to have the altered BRCA1 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B48c.

- d. Would be able to follow through and cope effectively over the long haul if you were found to have the altered BRCA1 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B48d.

RELATIONSHIPS SECTION

1. Is there anyone in your life with whom you can share your most private feelings without holding back? C21.
(1) ☐ Yes (5) ☐ No
2. If married, can you share your most private feelings with your husband without holding back? C21a.
(1) ☐ Yes (5) ☐ No
3. If married, is there anyone besides your husband with whom you can share your most private feelings without holding back? C21b.
(1) ☐ Yes (5) ☐ No
-

LIFE EVENTS SECTION

1. Have any of the following events happened to you in the past six months? D1(a-m)
(Check All That Apply)
- | | |
|--|---|
| a. <input type="checkbox"/> You retired, were fired, or laid off from work. | g. <input type="checkbox"/> A close family member was seriously ill or injured. |
| b. <input type="checkbox"/> You were unemployed and looking for work. | h. <input type="checkbox"/> You had a marital separation or divorce. |
| c. <input type="checkbox"/> Your spouse retired, was fired, or laid off from work. | i. <input type="checkbox"/> You had serious troubles with relatives or close friends. |
| d. <input type="checkbox"/> Your spouse was unemployed and looking for work. | j. <input type="checkbox"/> Your spouse had troubles or difficulties with relatives or close friends. |
| e. <input type="checkbox"/> You had problems with the police or court. | k. <input type="checkbox"/> A close family member died. |
| f. <input type="checkbox"/> You got into serious financial difficulties. | l. <input type="checkbox"/> A close friend or relative died. |
| | m. <input type="checkbox"/> You were seriously ill or injured. |
-

MARRIAGE SECTION

The following questions apply to persons who are married or living with a partner. If you are not married or living with a partner, check the appropriate box and please skip to the Next Section, MOOD.

Not married or living with a partner ☐

E-a.

Most persons have disagreements in their relationships. Please check the appropriate box to indicate the extent of agreement or disagreement experienced between you and your partner **DURING THE PAST MONTH**, regarding.

		6	5	4	3	2	1	
		<i>Always Agree</i>	<i>Almost Always Agree</i>	<i>Occasionally Disagree</i>	<i>Frequently Disagree</i>	<i>Almost Always Disagree</i>	<i>Always Disagree</i>	
1.	Religious matters							H3.
2.	Demonstration of affection							H4.
3.	Sex relations							H6.
4.	Conventionality (correct or proper behavior)							H7.
5.	Making major decisions							H12.
6.	Career decisions							H15.

		1	2	3	4	5	6	
		<i>All of the time</i>	<i>Most of the time</i>	<i>More often than most</i>	<i>Occasionally</i>	<i>Rarely</i>	<i>Never</i>	
7.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?							H16.
8.	Do you ever regret that you married (or are living together)?							H20.
9.	How often do you and your husband/partner quarrel?							H21.
10.	How often do you and your husband/partner "get on each other's nerves?"							H22.

		5	4	3	2	1
		<i>All of Them</i>	<i>Most of Them</i>	<i>Some of Them</i>	<i>Very few of Them</i>	<i>None of Them</i>
11.	Do you and your husband/partner engage in outside interests together?					

H24.

How often would you say the following events occur between you and your husband/partner?

		1	2	3	4	5	6
		<i>Never</i>	<i>Less than once a month</i>	<i>About twice a month</i>	<i>About twice a week</i>	<i>Once a day</i>	<i>More Often</i>
12.	Have a stimulating exchange of ideas						
13.	Calmly discuss something						
14.	Work together on a project						

H25.

H27.

H28.

15. Considering **only the positive feelings** you have toward your husband/partner, and **ignoring the negative ones**, please rate how positive these feelings are:

H33.

Not At All Positive								Extremely Positive	
1	2	3	4	5	6	7	8	9	10

16. Considering **only the negative feelings** you have toward your husband/partner, and **ignoring the positive ones**, please rate how negative these feelings are:

H34.

Not At All Negative								Extremely Negative	
1	2	3	4	5	6	7	8	9	10

17. The following questions concern your husband's involvement in your health care.

		<div>Never</div> <div>Very Often</div>					
a.	How often does your husband/partner go with you to your appointments with doctors?	1	2	3	4	5	H35a.
b.	How often does your husband/partner talk with your doctor or other medical personnel about your risk for breast cancer?	1	2	3	4	5	H35b.
c.	How often does your husband/partner keep track of what you need to do about your risk for breast cancer?	1	2	3	4	5	H35c.
d.	How often does your husband/partner change his activities to assist you in your health care?	1	2	3	4	5	H35d.

18. Has your husband/partner attended individual, family or group sessions to become informed about your risk for breast cancer and what can be done? H36.

1

5

Yes ☐ No ☐

19. How much contact has your husband/partner had with medical personnel concerning your risk for breast cancer? H37.

Very Little or None

A lot

1 2 3 4 5 6 7

20. Do you feel your husband/partner is adequately informed concerning your risk for breast cancer and what can be done about it? H38.

Not at All

Very Much

1 2 3 4 5 6 7

21. To what extent are you satisfied with your husband/partner's involvement in your health care? H39.

Not at All

Very Much

1 2 3 4 5 6 7

MOOD SECTION

1. Have you **ever in your lifetime** had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I14
- 1 5
☐ Yes ☐ No
- 1a. If **yes**, there was such a two-week period, did your work or relationships suffer? I14a.
- 1 5
☐ Yes ☐ No
- 1b. If **yes**, there was such a two-week period, did you get counseling or psychotherapy? I14b.
- 1 5
☐ Yes ☐ No
- 1c. If **yes**, there was such a two-week period, did you get medication for this condition? I14c.
- 1 5
☐ Yes ☐ No
2. In **the past 6 months**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I12.
- 1 5
☐ Yes ☐ No
- 2a. If **yes**, there was such a two-week period in **the past 6 months**, did your work or relationships suffer? I12a.
- 1 5
☐ Yes ☐ No
- 2b. If **yes**, there was such a two-week period in **the past 6 months**, did you get counseling or psychotherapy? I12b.
- 1 5
☐ Yes ☐ No
- 2c. If **yes**, there was such a two-week period in **the past 6 months**, did you get medication for this condition? I12c.
- 1 5
☐ Yes ☐ No
3. Are you **currently** receiving counseling, psychotherapy or medication for depression or emotional problems? I13.
- 1 5
☐ Yes ☐ No

SYMPTOMS OF STRAIN SECTION

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the **Past Three Months**.*

		<i>1</i> <i>Not at all</i>	<i>2</i> <i>A little</i>	<i>3</i> <i>Quite a bit</i>	<i>4</i> <i>Extremely</i>	
1.	Suddenly scared for no reason					K1.
2.	Feeling fearful					K2.
3.	Faintness, dizziness, or weakness					K3.
4.	Nervousness or shakiness inside					K4.
5.	Heart pounding or racing					K5.
6.	Trembling					K6.
7.	Feeling tense or keyed up					K7.
8.	Headaches					K8.
9.	Spells of terror or panic					K9.
10.	Feeling restless, can't sit still					K10.
11.	Feeling low in energy--slowed down					K11.
12.	Blaming yourself for things					K12.
13.	Crying easily					K13.
14.	Loss of sexual interest or pleasure					K14.
15.	Poor appetite					K15.
16.	Difficulty falling asleep, staying asleep					K16.
17.	Feeling hopeless about the future					K17.
18.	Feeling blue					K18.
19.	Feeling lonely					K19.
20.	Feeling trapped or caught					K20.
21.	Worrying too much about things					K21.
22.	Feeling no interest in things					K22.
23.	Thoughts of ending your life					K23.
24.	Feeling everything is an effort					K24.
25.	Feelings of worthlessness					K25.

COPING SECTION

1. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of your risk for breast cancer. For each of the statements below, indicate the degree to which your life is affected positively by your risk of breast cancer.

		<i>Not At All</i>	<i>A Very Small Degree</i>	<i>A Small Degree</i>	<i>A Moderate Degree</i>	<i>A Great Degree</i>	<i>A Very Great Degree</i>	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e.
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h.
i.	A willingness to express my emotions.	1	2	3	4	5	6	L6i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6j.
k.	Appreciating each day.	1	2	3	4	5	6	L6k.
l.	Having compassion for others.	1	2	3	4	5	6	L6l.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n.

2. This set of questions deals with ways you've been coping with the stress in your life that comes with being at risk for breast cancer. There are many ways people try to deal with problems. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know *to what extent* you've been doing what the item says, how *much* or how *frequently*. Don't answer on the basis of whether it seems to be working but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>	
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4	L7a.
b.	I've been concentrating my efforts on doing something about my situation.	1	2	3	4	L7b.
c.	I've been saying to myself "this isn't possible."	1	2	3	4	L7c.
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4	L7d.
e.	I've been getting emotional support from others.	1	2	3	4	L7e.
f.	I've been giving up trying to deal with it.	1	2	3	4	L7f.
g.	I've been taking action to try to make the situation better.	1	2	3	4	L7g.
h.	I've been refusing to believe that it is possible that I have the gene.	1	2	3	4	L7h.
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	L7i.
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	L7j.
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4	L7k.
l.	I've been trying to come up with a strategy about what to do.	1	2	3	4	L7l.
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7m.

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>
n.	I've been giving up the attempt to cope.	1	2	3	4
o.	I've been accepting the possibility that I might have the gene.	1	2	3	4
p.	I've been expressing my negative feelings.	1	2	3	4
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
r.	I've been learning to live with the possibility that I might have the gene.	1	2	3	4
s.	I've been thinking hard about what steps to take.	1	2	3	4
t.	I've been praying or meditating.	1	2	3	4
u.	I've been making fun of the situation.	1	2	3	4

L7n.

L7o.

L7p.

L7q.

L7r.

L7s.

L7t.

L7u.

3. The following items are to be answered only by those women who are married or living with a partner.

☐ Not married or living with a partner

L8.

(Skip to Last Section on page 15, Background Data)

		<i>I haven't been doing this at all 1</i>	<i>I've been doing this a little bit 2</i>	<i>I've been doing this some 3</i>	<i>I've been doing this a lot 4</i>
a.	I've been denying or hiding my anger around my husband/partner.	1	2	3	4
b.	I've been denying or hiding my worries around my husband/partner.	1	2	3	4
c.	I've been avoiding talking about my problems around my husband/partner.	1	2	3	4
d.	I've acted more positive around my husband/partner than I feel.	1	2	3	4

L8a.

L8b.

L8c.

L8d.

BACKGROUND DATA

These are a few questions about your religious background, that we forgot to ask on the original questionnaire.

1. Religion: Catholic (1) ☐ Protestant (4) ☐ A 3.
Jewish (2) ☐ Buddhist (5) ☐
Muslim (3) ☐ Other (6) ☐
None (7) ☐

- 1a. How often do you attend religious services? A 3a.
(1) (5)
☐ Less Often Than Once a Month ☐ A Few Times A Month or More

- 1b. How important are religious and spiritual beliefs in your life? A 3b.
Not at All Very Important
1 2 3 4 5

Once again, We thank you for all of your valued participation in this study.



WOMEN'S HEALTH STUDY

Sister Questionnaire

Today's Date _____

ID _____

SISTER QUESTIONNAIRE

HEALTH SECTION

1. Have you ever been diagnosed with Breast cancer? (1) ☐ Yes (5) ☐ No **B1u.**
2. Have you ever been diagnosed with Ovarian cancer? (1) ☐ Yes (5) ☐ No **B5.**

Please answer the following questions only if you have been diagnosed at any time with breast or ovarian cancer.

I have never been diagnosed with breast or ovarian cancer. ☐ Skip to 11

3. When were you first diagnosed with breast cancer? **B1.**
Month _____ Year _____ ☐ Not Applicable
4. When were you first diagnosed with ovarian cancer? **B5a.**
Month _____ Year _____ ☐ Not Applicable
5. Have you received any of the following treatments?
- | | | | |
|--------------|----------------------------------|---------------------------------|-------------|
| Chemotherapy | (1) <input type="checkbox"/> Yes | (5) <input type="checkbox"/> No | B4a. |
| Radiation | (1) <input type="checkbox"/> Yes | (5) <input type="checkbox"/> No | B4b. |
| Surgery | (1) <input type="checkbox"/> Yes | (5) <input type="checkbox"/> No | B4c. |
6. Have you ever had any of the following surgical procedures?
- 6a. **Lumpectomy** (Removal of lump from breast) **B6a.**
(1) ☐ Yes (5) ☐ No If yes, when? Month _____ Year _____ **B6a2.**
- 6b. **Oophorectomy** (Removal of ovaries) **B6b.**
(1) ☐ Yes (5) ☐ No If yes, when? Month _____ Year _____ **B6b2.**
- 6c. **Unilateral mastectomy** (Removal of one breast) **B6c.**
(1) ☐ Yes (5) ☐ No If yes, when? Month _____ Year _____ **B6c2.**
- 6d. **Hysterectomy** (Removal of uterus) **B6d.**
(1) ☐ Yes (5) ☐ No If yes, when? Month _____ Year _____ **B6d2.**
- 6e. **Bilateral mastectomy** (Removal of both breasts) **B6e.**
(1) ☐ Yes (5) ☐ No If yes, when? Month _____ Year _____ **B6e2.**

7. Do you currently consider yourself in remission? **B3.**
 (1) ☐ Yes (5) ☐ No (3) ☐ I Don't Know

8. Have you ever had a recurrence of breast or ovarian cancer? **B100.**
 (1) ☐ Yes (5) ☐ No (3) ☐ I Don't Know

9. Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to **the average woman**? (Please circle one) **B7.**

Much Less Likely			Much More Likely	
1	2	3	4	5

10. Before your diagnosis of breast cancer, how likely did you think you were to develop breast cancer, compared to the **women in your family**? (Please circle one) **B8.**

Much Less Likely			Much More Likely	
1	2	3	4	5

*Skip to
Question 13*

11. How likely did you think you are to develop breast cancer, compared to **the average woman**? (Please circle one) **B7a.**

Much Less Likely			Much More Likely	
1	2	3	4	5

12. How likely did you think you are to develop breast cancer, compared to **the women in your family**? (Please circle one) **B8a.**

Much Less Likely			Much More Likely	
1	2	3	4	5

13. When was the last time you had a mammography? **B32.**
 _____Month _____Year ☐ This question does not apply because of surgery.
 (-8)

14. How many times have you conducted a breast self-examination (BSE) in the past six months? **B33.**
 _____times ☐ This question does not apply because of surgery.
 (-8)

15. In general, would you say your health is:

I1.

☐ Excellent
(1)

☐ Very Good
(2)

☐ Good
(3)

☐ Fair
(4)

☐ Poor
(5)

16. Compared to one year ago, how would you rate your health in general now?
(Please Check one only)

I2.

- (1) ☐ Much better now than one year ago
 (2) ☐ Somewhat better now than one year ago
 (3) ☐ About the same as one year ago
 (4) ☐ Somewhat worse now than one year ago
 (5) ☐ Much worse than one year ago

FAMILY HISTORY SECTION

In the next set of questions, we are interested in learning about your family's experience with breast cancer.

1. Have any of your relatives been diagnosed with breast cancer?

B91.

(1) ☐ Yes (5) ☐ No (3) ☐ I Don't Know

2. If Yes, how many of the following relatives been affected by (diagnosed with) breast cancer? (How many relatives for each category where applicable?)

	<u>Relative:</u>	<u>How Many?</u>
a.	Sister(s)	
b.	Mother	
c.	Grandmother(s) Maternal	
d.	Grandmother(s) Paternal	
e.	Aunt(s) Maternal	
f.	Aunt(s) Paternal	
g.	Cousin(s) Maternal	
h.	Cousin(s) Paternal	
i.	Wife	
j.	Daughter(s)	

B92a.

B92b.

B92c1.

B92c2.

B92d1.

B92d2.

B92e1.

B92e2.

B92f.

B92g.

3. Do you think that your family is at an increased risk for breast cancer compared with other families?

B99.

(1) ☐ Yes (5) ☐ No (3) ☐ I Don't Know

IF ANSWERED NO, GO TO QUESTION 7

4. How distressing is it for you to know that women in your family may be at increased risk for breast cancer because of their family history?

B66a.

Not At All Distressing		Very Distressing		
1	2	3	4	5

5. Do you discuss your family's **increased risk for breast cancer** with any of the following women in your family? (Circle *Not Applicable* if you do not have any living relatives in that category.)

		<i>Yes</i>	<i>No</i>	<i>Not Applicable</i>	
a.	Mother	1	5	9	B93a.
b.	Grandmother(s)	1	5	9	B93b.
c.	Aunt(s)	1	5	9	B93c.
d.	Cousin(s)	1	5	9	B93d.
e.	Wife	1	5	9	B93e.
f.	Daughter(s)	1	5	9	B93f.
f.	Other women family members	1	5	9	B93g.

6. Compared to how often you now talk to the women in your family about their **risk for breast cancer**, how much would you prefer to talk to them about this topic?

B94.

A Lot Less	A Little Less	Same Amount	A Little More	A Lot More
1	2	3	4	5

7. Do you wish you had more information about your family's risk for breast cancer?

B97.

(1) ☐ Yes (5) ☐ No (3) ☐ No Opinion

8. How often do you discuss your family's risk for breast cancer with **your sister who gave us your name**?

B75.

Never	Rarely	Sometimes	Often
1	2	3	4

- 8a. If you have these discussions, who generally initiates them?

B75a.

You	Your Sister	Equally	No discussions
1	2	3	4

- 8b. How satisfied are you with these discussions?

B75b.

Not At All	A Little	Somewhat	A Great Deal	No discussions
1	2	3	4	5

9. How often does **your sister** seek your support concerning the risk of breast cancer to women in your family?

B49a.

Never	Rarely	Sometimes	Often
1	2	3	4

10. How much of a **burden** is this on you?

B50.

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

GENETIC TESTING SECTION

Now, we have some questions about breast cancer diagnosis, treatment, and genetic testing.

1. We would like to know how much you have been informed about breast cancer. To what extent do you agree with the following statements?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		<i>I Don't Know</i>
		1	2	3	4	5	9
a.	Mammography is effective in the early detection of breast cancer in women.						

B20a.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		<i>I Don't Know</i>	
b.	Breast cancer that is detected early is curable.	1	2	3	4	5	9	B20b.
c.	Mammography can detect lumps that cannot be felt by a woman or by her doctor.	1	2	3	4	5	9	B20c.
d.	If more women went for breast screening, there would be fewer deaths from breast cancer.	1	2	3	4	5	9	B20d.
e.	If a lump is found in a woman's breast, it is usually too late to do anything about it.	1	2	3	4	5	9	B20f.
f.	There are so many things that could happen to someone's health that it is pointless for a woman to worry about breast cancer.	1	2	3	4	5	9	B20i.

There is a test now available that will allow individuals to learn whether they have the altered gene which conveys an increased risk for developing breast cancer.

2. Were you aware that **women** are being offered the opportunity to take this test? **B77a.**
 (1) ☐ Yes (5) ☐ No

3. Do you discuss **genetic testing for breast cancer** susceptibility with any of the following women in your family? (Circle *Not Applicable* if you do not have any living relatives in that category.)

		<i>Yes</i>	<i>No</i>	<i>Not Applicable</i>	
a.	Sister(s)	1	5	9	B95a.
b.	Mother	1	5	9	B95b.
c.	Grandmother(s)	1	5	9	B95c.
d.	Aunt(s)	1	5	9	B95d.
e.	Cousin(s)	1	5	9	B95e.
f.	Wife	1	5	9	B95f.
f.	Daughter(s)	1	5	9	B95g.
g.	Other women family members	1	5	9	B95h.

4. Compared to how often you now talk to the women in your family about **genetic testing for breast cancer**, how much would you prefer to talk to them about this topic?

B96.

A Lot Less	A Little Less	Same Amount	A Little More	A Lot More
1	2	3	4	5

5. Do you wish you had more information about genetic testing?

B98.

(1) ☐ Yes (5) ☐ No (3) ☐ No Opinion

6. How often do you discuss genetic testing for breast cancer with **your sister**?

B51a.

Never	Rarely	Sometimes	Often
1	2	3	4

- 6a. If you have these discussions, who generally initiates them?

B52a.

You	Your Sister	Equally	No discussions
1	2	3	4

- 6b. How satisfied are you with these discussions?

B53.

Not At All	A Little	Somewhat	A Great Deal	No discussions
1	2	3	4	5

7. What are **your** plans concerning this genetic test at the present time?
(Please check one response).

B15c.

- (1)_____ I will definitely take the test soon.
 (2)_____ I will definitely take the test, but I am not sure when.
 (3)_____ I will probably take the test.
 (4)_____ I am undecided whether I will take the test.
 (5)_____ I will probably not take the test.
 (6)_____ I will definitely not take the test.

8. If you think you will probably or definitely take the test, what are your reasons for doing so? **B16a.**
(Please check all that apply).

- (1)_____ To make decisions about family planning.
(2)_____ To find out the risk that may be transmitted to my children.
(3)_____ To find out about the risk to a daughter who is too young to be tested.
(4)_____ Family members want me to get testing.
(5)_____ I just want to know whether I have the altered gene.
(6)_____ I am worried about my own risk for cancer.
(7)_____ Other (describe) _____

9. If you **do not** think you will probably or definitely take the test, what are your reasons for not doing so? (Please check all that apply). **B17a.**

- (1)_____ I am happier not knowing.
(2)_____ I do not see any reason for learning if I have the altered gene.
(3)_____ It would be too upsetting to learn that I have the altered gene.
(4)_____ I am too worried about women in my family.
(5)_____ I believe I already know whether I have the altered gene.
(6)_____ There would not be much I could do if I found out I had the altered gene.
(7)_____ I do not feel able emotionally to deal with testing.
(8)_____ Family members do not want me to get testing.
(9)_____ Risk to my insurance coverage.
(10)_____ Too much hassle
(11)_____ Other (describe) _____

10. How distressing is it for you to know that you may carry the altered gene which conveys an increased risk of breast cancer? **B76.**

Not At All Distressed		Very Distressed		
1	2	3	4	5

11. Overall, how important are the opinions of the following family members in your decision whether to be tested for an alteration in a breast cancer susceptibility gene? (Circle *Not Applicable* if you do not have any relatives in that category.)

		Not At All	A Little	Some-what	A Great Deal	Not Applicable
a.	Sister(s)'s opinion matters	1	2	3	4	9
b.	Spouse/Partner's opinion matters	1	2	3	4	9
c.	Mother's opinion matters	1	2	3	4	9
d.	Daughter's opinion matters	1	2	3	4	9
e.	Other family member(s)'s opinions matter	1	2	3	4	9

B78a.

B78b.

B78c.

B78d.

B78e.

12. How pressured do you feel from the following family members to get tested for the altered gene? (Circle *Not Applicable* if you do not have any relatives in that category.)

		Not At All	A Little	Some-what	A Great Deal	Not Applicable
a.	Sister(s)	1	2	3	4	9
b.	Spouse/Partner	1	2	3	4	9
c.	Mother	1	2	3	4	9
d.	Daughter	1	2	3	4	9
e.	Other family member(s)	1	2	3	4	9

B79a.

B79b.

B79c.

B79d.

B79e.

13. How much of a **burden** is it **on you** when the women in your family pressure you to get tested for the altered gene?

B80.

No Burden	A Little Burden	Some Burden	A Great Burden	Not applicable, No Pressure
1	2	3	4	5

14. How distressed would you be if you took the test and found that you **did not** have the altered gene which conveys increased risk of breast cancer?

B70a.

Not At All Distressed				Very Distressed
1	2	3	4	5

15. If you were to take the test and find out that you **did not have** the altered gene which conveys increased risk for breast cancer, what would you expect your reactions to be?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
a.	I would feel wonderful.	1	2	3	4	5	B81a.
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	B81b.
c.	I would feel relieved.	1	2	3	4	5	B81c.
d.	I would not believe the results.	1	2	3	4	5	B81d.
e.	I would fall apart emotionally.	1	2	3	4	5	B81e.
f.	I would feel guilty.	1	2	3	4	5	B81f.
g.	I would still feel anxious.	1	2	3	4	5	B81g.
h.	I would feel angry.	1	2	3	4	5	B81h.
i.	I would feel prepared for the future.	1	2	3	4	5	B81i.
j.	I would feel I had done all I needed to do.	1	2	3	4	5	B81j.
k.	I would not feel very differently.	1	2	3	4	5	B81k.

16. How distressed would you be if you took the test and found that you **did have** the altered gene which conveys increased risk for breast cancer?

B69a.

Not At All Distressed		Very Distressed		
1	2	3	4	5

17. If you were to take the test and find out that you **had** the altered gene, what would you expect your reactions to be?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
a.	I would feel relieved about being more certain.	1	2	3	4	5	B82a.
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	B82b.
c.	I would not believe the results.	1	2	3	4	5	B82c.
d.	I would feel guilty.	1	2	3	4	5	B82d.
e.	I would be depressed.	1	2	3	4	5	B82e.
f.	I would feel worried about the future.	1	2	3	4	5	B82f.
g.	I would just fall apart emotionally.	1	2	3	4	5	B82g.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>	
		1	2	3	4	5
h.	I would feel anxious.	1	2	3	4	5
i.	I would feel angry.	1	2	3	4	5
j.	I would not feel very differently.	1	2	3	4	5

B82h.

B82i.

B82j.

		<i>Not At All</i>			<i>All The Time</i>	
		1	2	3	4	5
18.	How often do you worry about having the altered gene associated with risk for breast cancer among women?	1	2	3	4	5
19.	To what extent do any worries you have about this genetic alteration interfere with every day life?	1	2	3	4	5
20.	How often do you worry about women in your family developing breast cancer?	1	2	3	4	5
21.	How often do you worry about developing cancer yourself?	1	2	3	4	5
22.	How much do worries about developing cancer interfere with your everyday life?	1	2	3	4	5

B83.

B84.

B85.

B86.

B87.

23. How likely do you think it is that you have the altered gene which conveys increased risk for breast cancer in women relatives? (Please circle one)

B88.

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
0	1	2	3	4	5	6	7	8	9	10

24. How much would it affect your health in the future if you had the altered gene which conveys increased risk for breast cancer in women relatives?

B89.

☐ Not at All ☐ A Little ☐ Somewhat ☐ A Great Deal ☐ I Don't Know
 (1) (2) (3) (4) (5)

25. Overall, what do you think your risk is of developing cancer (or developing cancer again) in the future?

B90.

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
0	1	2	3	4	5	6	7	8	9	10

SYMPTOMS OF STRAIN SECTION

Listed Below Are Some Symptoms Of Strain That People Sometimes Have. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the **Past Three Months.***

		<u>Not at all</u>	<u>A little</u>	<u>Quite a bit</u>	<u>Extremely</u>
1.	Suddenly scared for no reason	1	2	3	4
2.	Feeling fearful	1	2	3	4
3.	Faintness, dizziness, or weakness	1	2	3	4
4.	Nervousness or shakiness inside	1	2	3	4
5.	Heart pounding or racing	1	2	3	4
6.	Trembling	1	2	3	4
7.	Feeling tense or keyed up	1	2	3	4
8.	Headaches	1	2	3	4
9.	Spells of terror or panic	1	2	3	4
10.	Feeling restless, can't sit still	1	2	3	4
11.	Feeling low in energy--slowed down	1	2	3	4
12.	Blaming yourself for things	1	2	3	4
13.	Crying easily	1	2	3	4
14.	Loss of sexual interest or pleasure	1	2	3	4
15.	Poor appetite	1	2	3	4
16.	Difficulty falling asleep, staying asleep	1	2	3	4
17.	Feeling hopeless about the future	1	2	3	4
18.	Feeling blue	1	2	3	4
19.	Feeling lonely	1	2	3	4
20.	Feeling trapped or caught	1	2	3	4
21.	Worrying too much about things	1	2	3	4
22.	Feeling no interest in things	1	2	3	4
23.	Thoughts of ending your life	1	2	3	4
24.	Feeling everything is an effort	1	2	3	4
25.	Feelings of worthlessness	1	2	3	4

K1.

K2.

K3.

K4.

K5.

K6.

K7.

K8.

K9.

K10.

K11.

K12.

K13.

K14.

K15.

K16.

K17.

K18.

K19.

K20.

K21.

K22.

K23.

K24.

K25.

FAMILY RELATIONSHIPS SECTION

1. Please indicate the extent to which each of the following items currently describes **the family in which you grew up**.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
a.	Planning family activities is difficult because we misunderstand each other.	1	2	3	4	5	M1.
b.	In times of crisis we can turn to each other for support.	1	2	3	4	5	M2.
c.	We cannot talk to each other about the sadness we feel.	1	2	3	4	5	M3.
d.	Individuals are accepted for who they are.	1	2	3	4	5	M4.
e.	We avoid discussing our fears and concerns.	1	2	3	4	5	M5.
f.	We can express feelings to each other.	1	2	3	4	5	M6.
g.	There are lots of bad feelings in the family.	1	2	3	4	5	M7.
h.	We feel accepted for who we are.	1	2	3	4	5	M8.
i.	Making decisions is a problem for our family.	1	2	3	4	5	M9.
j.	We are able to make decisions about how to solve problems.	1	2	3	4	5	M10.
k.	We don't get along well together.	1	2	3	4	5	M11.
l.	We confide in each other.	1	2	3	4	5	M12.

2. Is there anyone in your life with whom you can share your most private feelings without holding back? C21.

☐ Yes ☐ No

- 2a. Do you have that kind of relationship with **your sister** (who gave us your name)? C21c.

☐ Yes ☐ No

3. How often do you talk to **your sister**? (check one) C22.

☐ Most every day
☐ A few times a week
☐ A few times a month
☐ Once a month
☐ Less than once a month
☐ Less than once a year
☐ Never

BACKGROUND DATA SECTION

Now, we'd like to know more about you.

1. Date of Birth _____ Month _____ Day _____ Year A1.

2. Ethnic Background:

White	<input type="checkbox"/> 1	Black	<input type="checkbox"/> 4		
Hispanic	<input type="checkbox"/> 2	Asian	<input type="checkbox"/> 5		
Native American	<input type="checkbox"/> 3	Other	<input type="checkbox"/> 6		

A2.

3. Religion:

Catholic	<input type="checkbox"/> 1	Protestant	<input type="checkbox"/> 4		
Jewish	<input type="checkbox"/> 2	Buddhist	<input type="checkbox"/> 5		
Muslim	<input type="checkbox"/> 3	Other	<input type="checkbox"/> 6		
		None	<input type="checkbox"/> 7		

A3.

- 3a. How often do you attend religious services? A3a.

<input type="checkbox"/> 1 Less Than Once a Month	<input type="checkbox"/> 5 A Few Times A Month or More
---	--

- 3b. How important are religious and spiritual beliefs in your life? A3b.

Not at All				Very Important
1	2	3	4	5

4. Are you currently (**please check one**)? A4.

1 <input type="checkbox"/> Single	
2 <input type="checkbox"/> Married	
3 <input type="checkbox"/> Not married, but living in a steady, marriage-like relationship	
4 <input type="checkbox"/> Separated	
5 <input type="checkbox"/> Divorced	
6 <input type="checkbox"/> Widowed	

5. If you **are** currently married, what was the date of your current marriage? A5.

Month _____	Year _____
-------------	------------

- 5a. Is this your first marriage? (1) ☐ Yes (5) ☐ No A5a.

6. How many children do you have? _____ A6.

6a. Number of children living at home? _____	
6b. Number who are under age 6? _____	
6c. Number of Daughters? _____	

7. Do you plan to have more children? (1) ☐ Yes (5) ☐ No (3) ☐ Undecided A12.

7a. If yes, how many more children? _____	
---	--

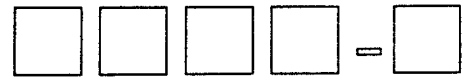
A12a.

8. Are you currently working for pay outside the home? A 7.
 (1) ☐ Yes (5) ☐ No
9. If **yes**, about how many hours per week are you working for pay? A 8.
 Less than 10 10-20 21-30 31-40 41 or more
☐ (1) ☐ (2) ☐ (3) ☐ (4) ☐ (5)
10. What is the highest level of education you have completed? (**Check one**) A 9.
- | | |
|---|--|
| 1 <input type="checkbox"/> Less than 9th grade | 5 <input type="checkbox"/> Completed college |
| 2 <input type="checkbox"/> Dropped out of high school | 6 <input type="checkbox"/> Some graduate or professional training |
| 3 <input type="checkbox"/> Completed high school | 7 <input type="checkbox"/> Completed graduate or professional training |
| 4 <input type="checkbox"/> Some college | |

The following two questions are optional, but we hope that you will provide this information.

11. What is your household's total income? (**Check one**) A 10.
- | | | |
|---|---|--|
| (1) <input type="checkbox"/> Less than \$10,000 | (4) <input type="checkbox"/> \$30,000 to \$39,999 | (7) <input type="checkbox"/> \$60,000 to \$69,999 |
| (2) <input type="checkbox"/> \$10,000 to \$19,999 | (5) <input type="checkbox"/> \$40,000 to \$49,999 | (8) <input type="checkbox"/> Greater than \$69,999 |
| (3) <input type="checkbox"/> \$20,000 to \$29,999 | (6) <input type="checkbox"/> \$50,000 to \$59,999 | |
12. How many people (adults and children) does this income support? _____ A 11.
-

THANK YOU VERY MUCH
FOR YOUR PARTICIPATION.



WOMEN'S HEALTH STUDY

Brother Questionnaire

Today's Date _____

ID _____

BROTHER QUESTIONNAIRE

FAMILY HISTORY SECTION

First, we are interested in learning about your family's experience with breast cancer.

1. Have any of your relatives been diagnosed with breast cancer? **B91.**

(1) ☐ Yes (5) ☐ No (3) ☐ I Don't Know

2. If **Yes**, how many of the following relatives been affected by (diagnosed with) breast cancer? (*Record the number of relatives for each category*)

	<u>Relative:</u>	<u>How Many?</u>	
a.	Sister(s)		B92a.
b.	Mother		B92b.
c.	Grandmother(s) Maternal		B92c1.
d.	Grandmother(s) Paternal		B92c2.
e.	Aunt(s) Maternal		B92d1.
f.	Aunt(s) Paternal		B92d2.
g.	Cousin(s) Maternal		B92e1.
h.	Cousin(s) Paternal		B92e2.
i.	Wife		B92f.
j.	Daughter(s)		B92g.

3. Do you think that your family is at an increased risk for breast cancer compared with other families? **B99.**

(1) ☐ Yes (5) ☐ No (3) ☐ I Don't Know

IF ANSWERED NO, GO TO QUESTION 7

4. How distressing is it for you to know that women in your family may be at increased risk for breast cancer because of their family history? **B66a.**

Not At All Distressing		Very Distressing		
1	2	3	4	5

5. Do you discuss your family's **increased risk for breast cancer** with any of the following women in your family? (Circle *Not Applicable* if you do not have any living relatives in that category.)

		<i>Yes</i>	<i>No</i>	<i>Not Applicable</i>	
a.	Mother	1	5	9	B93a.
b.	Grandmother(s)	1	5	9	B93b.
c.	Aunt(s)	1	5	9	B93c.
d.	Cousin(s)	1	5	9	B93d.
e.	Wife	1	5	9	B93e.
f.	Daughter(s)	1	5	9	B93f.
f.	Other women family members	1	5	9	B93g.

6. Compared to how often you now talk to the women in your family about their **risk for breast cancer**, how much would you prefer to talk to them about this topic? **B94.**

A Lot Less	A Little Less	Same Amount	A Little More	A Lot More
1	2	3	4	5

7. Do you wish you had more information about your family's risk of breast cancer? **B97.**

(1) ☐ Yes (5) ☐ No (3) ☐ No Opinion

8. How often do you discuss your family's risk for breast cancer with **your sister**? **B75.**

Never	Rarely	Sometimes	Often
1	2	3	4

8a. If you have these discussions, who generally initiates them?

B75a.

You	Your Sister	Equally	No discussions
1	2	3	4

8b. How satisfied are you with these discussions?

B75b.

Not At All	A Little	Somewhat	A Great Deal	No discussions
1	2	3	4	5

9. How often does **your sister** seek your support concerning the risk of breast cancer to women in your family?

B49a.

Never	Rarely	Sometimes	Often
1	2	3	4

10. How much of a **burden** is this on you?

B50.

Not At All	A Little	Somewhat	A Great Deal
1	2	3	4

GENETIC TESTING SECTION

Now, we have some questions about breast cancer diagnosis, treatment, and genetic testing.

1. We would like to know how much you have been informed about breast cancer. To what extent do you agree with the following statements?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		<i>I Don't Know</i>	
a.	Mammography is effective in the early detection of breast cancer in women.	1	2	3	4	5	9	B20a.
b.	Breast cancer that is detected early is curable.	1	2	3	4	5	9	B20b.
c.	Mammography can detect lumps that cannot be felt by a woman or by her doctor.	1	2	3	4	5	9	B20c.

d.	If more women went for breast screening, there would be fewer deaths from breast cancer.	1	2	3	4	5	9	B20d.
e.	If a lump is found in a woman's breast, it is usually too late to do anything about it.	1	2	3	4	5	9	B20f.
f.	There are so many things that could happen to someone's health that it is pointless for a woman to worry about breast cancer.	1	2	3	4	5	9	B20i.

There is a test now available that will allow individuals to learn whether they have the altered gene which conveys an increased risk for developing breast cancer.

2. Were you aware that **women** are being offered the opportunity to take this test? B77a.
 (1) ☐ Yes (5) ☐ No

3. Were you aware that **men** are being offered the opportunity to take this test? B77b.
 (1) ☐ Yes (5) ☐ No

4. Do you discuss **genetic testing for breast cancer** susceptibility with any of the following women in your family? (Circle *Not Applicable* if you do not have any living relatives in that category.)

		<i>Yes</i>	<i>No</i>	<i>Not Applicable</i>	
a.	Sister(s)	1	5	9	B95a.
b.	Mother	1	5	9	B95b.
c.	Grandmother(s)	1	5	9	B95c.
d.	Aunt(s)	1	5	9	B95d.
e.	Cousin(s)	1	5	9	B95e.
f.	Wife	1	5	9	B95f.
f.	Daughter(s)	1	5	9	B95g.
g.	Other women family members	1	5	9	B95h.

5. Compared to how often you now talk to the women in your family about **genetic testing for breast cancer**, how much would you prefer to talk to them about this topic? **B96.**

A Lot Less	A Little Less	Same Amount	A Little More	A Lot More
1	2	3	4	5

6. Do you wish you had more information about genetic testing? **B98.**
- (1) ☐ Yes (5) ☐ No (3) ☐ No Opinion

7. How often do you discuss genetic testing for breast cancer with **your sister**? **B51a.**

Never	Rarely	Sometimes	Often
1	2	3	4

- 7a. If you have these discussions, who generally initiates them? **B52a.**

You	Your Sister	Equally	No discussions
1	2	3	4

- 7b. How satisfied are you with these discussions? **B53.**

Not At All	A Little	Somewhat	A Great Deal	No discussions
1	2	3	4	5

8. What are **your** plans concerning this genetic test at the present time? **B15c.**
(Please check one response).

- (1)_____ I will definitely take the test soon.
- (2)_____ I will definitely take the test, but I am not sure when.
- (3)_____ I will probably take the test.
- (4)_____ I am undecided whether I will take the test.
- (5)_____ I will probably not take the test.
- (6)_____ I will definitely not take the test.

9. If you think you will probably or definitely take the test, what are your reasons for doing so? **B16a.**
(Please check all that apply).

- (1)_____ To make decisions about family planning.
- (2)_____ To find out the risk that may be transmitted to my children.
- (3)_____ To find out about the risk to a daughter who is too young to be tested.
- (4)_____ Family members want me to get testing.
- (5)_____ I just want to know whether I have the altered gene.
- (6)_____ I am worried about my own risk for cancer.
- (7)_____ Other (describe) _____

10. If you **do not** think you will probably or definitely take the test, what are your reasons for **not** doing so? **(Please check all that apply).** **B17a.**

- (1)_____ I am happier not knowing.
- (2)_____ I do not see any reason for learning if I have the altered gene.
- (3)_____ It would be too upsetting to learn that I have the altered gene.
- (4)_____ I am too worried about women in my family.
- (5)_____ I believe I already know whether I have the altered gene.
- (6)_____ There would not be much I could do if I found out I had the altered gene.
- (7)_____ I do not feel able emotionally to deal with testing.
- (8)_____ Family members do not want me to get testing.
- (9)_____ Risk to my insurance coverage.
- (10)_____ Too much hassle
- (11)_____ Other (describe) _____

11. How distressing is it for you to know that you may carry the altered gene which conveys an increased risk of breast cancer? **B76.**

Not At All Distressed		Very Distressed		
1	2	3	4	5

12. Overall, how important are the opinions of the following family members in your decision whether to be tested for an alteration in a breast cancer susceptibility gene?

		Not At All	A Little	Some-what	A Great Deal	Not Applicable
a.	Sister(s)'s opinion matters	1	2	3	4	9
b.	Wife's opinion matters	1	2	3	4	9
c.	Mother's opinion matters	1	2	3	4	9
d.	Daughter's opinion matters	1	2	3	4	9
e.	Other family member(s)'s opinions matter	1	2	3	4	9

B78a.

B78b.

B78c.

B78d.

B78e.

13. How pressured do you feel from the following family members to get tested for the altered gene? (Circle *Not Applicable* if you do not have any relatives in that category.)

		Not At All	A Little	Some-what	A Great Deal	Not Applicable
a.	Sister(s)	1	2	3	4	9
b.	Wife	1	2	3	4	9
c.	Mother	1	2	3	4	9
d.	Daughter	1	2	3	4	9
e.	Other family member(s)	1	2	3	4	9

B79a.

B79b.

B79c.

B79d.

B79e.

14. How much of a **burden** is it **on you** when the women in your family pressure you to get tested for the altered gene?

B80.

No Burden	A Little Burden	Some Burden	A Great Burden	Not applicable, No Pressure
1	2	3	4	5

15. How distressed would you be if you took the test and found that you **did not** have the altered gene which conveys increased risk of breast cancer?

B70a.

Not At All Distressed		Very Distressed		
1	2	3	4	5

16. If you were to take the test and find out that you **did not have** the altered gene which conveys increased risk for breast cancer, what would you expect your reactions to be?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
a.	I would feel wonderful.	1	2	3	4	5	B81a.
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	B81b.
c.	I would feel relieved.	1	2	3	4	5	B81c.
d.	I would not believe the results.	1	2	3	4	5	B81d.
e.	I would fall apart emotionally.	1	2	3	4	5	B81e.
f.	I would feel guilty.	1	2	3	4	5	B81f.
g.	I would still feel anxious.	1	2	3	4	5	B81g.
h.	I would feel angry.	1	2	3	4	5	B81h.
i.	I would feel prepared for the future.	1	2	3	4	5	B81i.
j.	I would feel I had done all I needed to do.	1	2	3	4	5	B81j.
k.	I would not feel very differently.	1	2	3	4	5	B81k.

17. How distressed would you be if you took the test and found that you **did have** the altered gene which conveys increased risk for breast cancer?

B69a.

Not At All Distressed		Very Distressed		
1	2	3	4	5

18. If you were to take the test and find out that you **had** the altered gene, what would you expect your reactions to be?

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
a.	I would feel relieved about being more certain.	1	2	3	4	5	B82a.
b.	I would feel I had been told what I knew all along.	1	2	3	4	5	B82b.
c.	I would not believe the results.	1	2	3	4	5	B82c.
d.	I would feel guilty.	1	2	3	4	5	B82d.
e.	I would be depressed.	1	2	3	4	5	B82e.
f.	I would feel worried about the future.	1	2	3	4	5	B82f.
g.	I would just fall apart emotionally.	1	2	3	4	5	B82g.

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
h.	I would feel anxious.	1	2	3	4	5	B82h.
i.	I would feel angry.	1	2	3	4	5	B82i.
j.	I would not feel very differently.	1	2	3	4	5	B82j.

		<i>Not At All</i>			<i>All The Time</i>		
19.	How often do you worry about having the altered gene associated with risk for breast cancer among women?	1	2	3	4	5	B83.
20.	To what extent do any worries you have about this genetic alteration interfere with every day life?	1	2	3	4	5	B84.
21.	How often do you worry about women in your family developing breast cancer?	1	2	3	4	5	B85.
22.	How often do you worry about developing cancer yourself?	1	2	3	4	5	B86.
23.	How much do worries about developing cancer interfere with your everyday life?	1	2	3	4	5	B87.

24. How likely do you think it is that you have the altered gene which conveys increased risk for breast cancer in women relatives? (Please circle one) **B88.**

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
0	1	2	3	4	5	6	7	8	9	10

25. How much would it affect your health in the future if you had the altered gene which conveys increased risk for breast cancer in women relatives? **B89.**

☐ Not at All ☐ A Little ☐ Somewhat ☐ A Great Deal ☐ I Don't Know
 (1) (2) (3) (4) (5)

26. Overall, what do you think your risk is of developing cancer in the future? **B90.**

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
0	1	2	3	4	5	6	7	8	9	10

SYMPTOMS OF STRAIN SECTION

Listed Below Are Some Symptoms Of Strain That People Sometimes Have. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the **Past Three Months.***

		<u>Not at all</u>	<u>A little</u>	<u>Quite a bit</u>	<u>Extremely</u>	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energy--slowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

FAMILY RELATIONSHIPS SECTION

1. Is there anyone in your life with whom you can share your most private feelings without holding back? C21.

(1) ☐ Yes (5) ☐ No

1a. Do you have that kind of relationship with **your sister** (who gave us your name)? C21c.

(1) ☐ Yes (5) ☐ No

2. How often do you talk to your sister? (**check one**) C22.

- | | |
|-------------------------------|----------------------------------|
| (1) _____ Most every day | (5) _____ Less than once a month |
| (2) _____ A few times a week | (6) _____ Less than once a year |
| (3) _____ A few times a month | (7) _____ Never |
| (4) _____ Once a month | |

3. Please indicate the extent to which each of the following items currently describes **the family in which you grew up.**

		<i>Strongly Disagree</i>			<i>Strongly Agree</i>		
		1	2	3	4	5	
3a.	Planning family activities is difficult because we misunderstand each other.						M1.
3b.	In times of crisis we can turn to each other for support.						M2.
3c.	We cannot talk to each other about the sadness we feel.						M3.
3d.	Individuals are accepted for who they are.						M4.
3e.	We avoid discussing our fears and concerns.						M5.
3f.	We can express feelings to each other.						M6.
3g.	There are lots of bad feelings in the family.						M7.
3h.	We feel accepted for who we are.						M8.
3i.	Making decisions is a problem for our family.						M9.
3j.	We are able to make decisions about how to solve problems.						M10.
3k.	We don't get along well together.						M11.
3l.	We confide in each other.						M12.

BACKGROUND DATA SECTION

Now, we'd like to know more about you.

1. Date of Birth _____Month _____Day _____Year **A 1.**
2. Ethnic Background: White ☐ 1 Black ☐ 4 **A 2.**
Hispanic ☐ 2 Asian ☐ 5
Native American ☐ 3 Other ☐ 6
3. Religion: Catholic ☐ 1 Protestant ☐ 4 **A 3.**
Jewish ☐ 2 Buddhist ☐ 5
Muslim ☐ 3 Other ☐ 6
None ☐ 7
- 3a. How often do you attend religious services? **A 3a.**
☐ 1 Less Than Once a Month ☐ 5 A Few Times A Month or More
- 3b. How important are religious and spiritual beliefs in your life? **A 3b.**
Not at All 1 2 3 4 5 Very Important
4. Are you currently (**please check one**)? **A 4.**
1 ☐ Single
2 ☐ Married
3 ☐ Not married, but living in a steady,
marriage-like relationship
4 ☐ Separated
5 ☐ Divorced
6 ☐ Widowed
5. If you **are** currently married, what was the date of your current marriage? **A 5.**
Month _____ Year _____
- 5a. Is this your first marriage? (1) ☐ Yes (5) ☐ No **A 5a.**
6. How many children do you have? _____ **A 6.**
6a. Number of children living at home? _____ **A 6a.**
6b. Number who are under age 6? _____ **A 6b.**
6c. Number of Daughters? _____ **A 6c.**
7. Do you plan to have more children? (1) ☐ Yes (5) ☐ No (3) ☐ Undecided **A 12.**
7a. If **yes**, how many more children? _____ **A 12a.**

8. In general, would you say your health is: I1.
- ☐ Excellent (1)
 ☐ Very Good (2)
 ☐ Good (3)
 ☐ Fair (4)
 ☐ Poor (5)
9. Are you currently working for pay outside the home? A7.
- (1) ☐ Yes (5) ☐ No
10. If **yes**, about how many hours per week are you working for pay? A8.
- Less than 10 10-20 21-30 31-40 41 or more
☐ (1) ☐ (2) ☐ (3) ☐ (4) ☐ (5)
11. What is the highest level of education you have completed? (**Check one**) A9.
- | | |
|---|--|
| 1 <input type="checkbox"/> Less than 9th grade | 5 <input type="checkbox"/> Completed college |
| 2 <input type="checkbox"/> Dropped out of high school | 6 <input type="checkbox"/> Some graduate or professional training |
| 3 <input type="checkbox"/> Completed high school | 7 <input type="checkbox"/> Completed graduate or professional training |
| 4 <input type="checkbox"/> Some college | |

The following two questions are optional, but we hope that you will provide this information.

12. What is your household's total income? (**Check one**) A10.
- | | | |
|---|---|--|
| (1) <input type="checkbox"/> Less than \$10,000 | (4) <input type="checkbox"/> \$30,000 to \$39,999 | (7) <input type="checkbox"/> \$60,00 to \$69,999 |
| (2) <input type="checkbox"/> \$10,000 to \$19,999 | (5) <input type="checkbox"/> \$40,000 to \$49,999 | (8) <input type="checkbox"/> Greater than \$69,999 |
| (3) <input type="checkbox"/> \$20,000 to \$29,999 | (6) <input type="checkbox"/> \$50,000 to \$59,999 | |
13. How many people (adults and children) does this income support? _____ A11.
-

THANK YOU VERY MUCH FOR YOUR PARTICIPATION.

☐ ☐ ☐ ☐ - ☐



WOMEN'S HEALTH STUDY

Post-Results Questionnaire

TODAY'S DATE _____

ID _____

POST-RESULTS ASSESSMENT

Genetic Testing Section

1. When did you receive your results of genetic testing?

B101.

(Month/Year) _____

2. What were the results of testing?

- 1 ☐ Positive for BRCA1/BRCA2
- 2 ☐ Negative for BRCA1/BRCA2, but at least one family member was found to be Positive
- 3 ☐ Negative for BRCA1/BRCA2 and all Family members who were tested were negative for BRCA1/BRCA2

2. Did you do any of the following *before* obtaining your results?

		<u>Yes</u>	<u>No</u>	
a.	Prophylactic Mastectomy	1	5	B102a.
b.	Prophylactic Oophorectomy	1	5	B102b.
c.	Regular Breast Self-Exams (Monthly)	1	5	B102c.
d.	Regular Physical Exams	1	5	B102d.
e.	Regular Mammograms	1	5	B102e.
f.	Encourage your relatives to be tested	1	5	B102f.
g.	Discourage your relatives from being tested	1	5	B102g.

3. Please rate the extent to which each of the following were your reasons for getting your results.

		<div> <i>Not at All</i> <i>Very Much So</i> </div>					
a.	To plan for the future.	1	2	3	4	5	B16b1.
b.	To reduce the uncertainty.	1	2	3	4	5	B16b2.
c.	To know I have to be more careful about doing breast self examinations and getting regular checkups.	1	2	3	4	5	B16b3.
d.	To make decisions about whether to get prophylactic surgery.	1	2	3	4	5	B16b4.
e.	To make decisions about family planning.	1	2	3	4	5	B16b5.
f.	To find out the risk that may be transmitted to my children.	1	2	3	4	5	B16b6.
g.	Family members wanted me to get testing.	1	2	3	4	5	B16b7.
h.	Other (describe)_____	1	2	3	4	5	B16b8.

4. Before getting your test results, how distressing had it been for you to know that your family may be at increased risk for breast cancer because of your family history?

Not At All Distressing		Very Distressing		
1	2	3	4	5

B66b.

5. How distressed **did you expect to be** when you were told you have an altered BRCA1/BRCA2 gene (before you received results)?

Not At All Distressed		Very Distressed		
1	2	3	4	5

B68b.

6. How distressed **were you** when you were told that you had an altered BRCA1 (or BRCA2) gene?

Not At All Distressed				Very Distressed
1	2	3	4	5

B69b.

7. Overall, do you regret the decision to obtain your results?

Not At All				Very Much So
1	2	3	4	5

B71a.

8. When you received your results, what were your immediate reactions?

		Not At All					Very Much So
		1	2	3	4	5	
a.	I felt relieved about being more certain.	1	2	3	4	5	B82a.
b.	I felt I had been told what I knew all along.	1	2	3	4	5	B82b.
c.	I did not believe the results.	1	2	3	4	5	B82c.
d.	I felt guilty.	1	2	3	4	5	B82d.
e.	I was depressed.	1	2	3	4	5	B82e.
f.	I worried about the future.	1	2	3	4	5	B82f.
g.	I thought I would just fall apart emotionally.	1	2	3	4	5	B82g.
h.	I felt anxious.	1	2	3	4	5	B82h.
i.	I felt angry.	1	2	3	4	5	B82i.

9. We are interested in the decisions women make after being notified of the results of their testing. After obtaining your results, which options are you now considering? Please circle one response.

		Definitely Will NOT Do	Probably Will NOT Do	Probably Will Do	Definitely Will Do	Done After Obtaining Results	Does Not Apply to Me	
a.	Prophylactic Oophorectomy	1	2	3	4	5	-8	B103a.
b.	Prophylactic Mastectomy	1	2	3	4	5	-8	B103b.
c.	Regular Breast Self-Exams (Monthly)	1	2	3	4	5	-8	B103c.
d.	Regular Physical Exams	1	2	3	4	5	-8	B103d.
e.	Regular Mammograms	1	2	3	4	5	-8	B103e.
f.	Encouraging my relatives to be tested	1	2	3	4	5	-8	B103f.
g.	Discouraging my relatives from being tested	1	2	3	4	5	-8	B103g.
h.	Telling some of my relatives what my results were	1	2	3	4	5	-8	B103h.
i.	Not telling some of my relatives what my results were	1	2	3	4	5	-8	B103i.

10. For each of the following areas of your life, please indicate how much these decisions/plans have been affected by the results of genetic testing?

		Not at all Affected			Very Much Affected		Not Applicable	
a.	Decisions about having children	1	2	3	4	5	-8	B35c.
b.	Decisions about forms of birth control	1	2	3	4	5	-8	B36c.
c.	Decisions about which steps to take to prevent breast cancer	1	2	3	4	5	-8	B37c.
d.	Decisions about work and career	1	2	3	4	5	-8	B38c.

		<i>Not at all Affected</i>			<i>Very Much Affected</i>		<i>Not Applicable</i>	
e.	Decisions about savings and financial planning	1	2	3	4	5	-8	B39c.
f.	Plans for your future	1	2	3	4	5	-8	B40c.
g.	Plans for your daughter's future	1	2	3	4	5	-8	B42c.

11. Do you feel you have enough information about breast cancer to make any decisions that might be necessary?

Not At All						Very Much	B43.
1	2	3	4	5	6	7	

12. Do you feel you have enough information about ovarian cancer to make any decisions that might be necessary?

Not At All						Very Much	B43a.
1	2	3	4	5	6	7	

13. Do you feel you were adequately informed about the benefits and drawbacks of genetic testing for risk of breast and ovarian cancer **before getting your results?**

Not At All						Very Much	B44a.
1	2	3	4	5	6	7	

14. Do you **now** feel you are adequately informed about what you can do to reduce your risk of breast cancer since you have an altered BRCA1/BRCA2 gene?

Not At All						Very Much	B45a.
1	2	3	4	5	6	7	

15. Do you **now** feel you are adequately informed about what you can do to reduce your risk of ovarian cancer since you have an altered BRCA1/BRCA2 gene?

Not At All						Very Much	B45b.
1	2	3	4	5	6	7	

16. Do you **now** feel you are adequately informed about the benefits and drawbacks of each option available to women who have an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B46a.

17. Do you feel you are adequately informed about what it will mean for your children that you have an altered BRCA1/BRCA2 gene?

Not At All						Very Much	Not Applicable
1	2	3	4	5	6	7	-8

B47a.

18. How confident are you that **you** will cope effectively with the finding that you have an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B48e.

19. How confident are you that **your family members** will cope effectively with the finding that you have an altered BRCA1/BRCA2 gene?

Not At All						Very Much
1	2	3	4	5	6	7

B48f.

Personal Attitudes Section

1. Now, we would like to ask you some questions about your concerns of breast cancer?

		Not At All				All The Time
a.	How often do you worry about developing breast cancer or developing breast cancer again?	1	2	3	4	5
b.	To what extent do these worries interfere with your every day life?	1	2	3	4	5
c.	How often do you worry about developing ovarian cancer or developing ovarian cancer again?	1	2	3	4	5

B27.

B28.

B110.

		<div> <i>Not.At</i> <i>All</i> </div> <div> <i>All The</i> <i>Time</i> </div>					
d.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B111.
e.	How often do you worry about having an altered gene associated with risk for breast or ovarian cancer?	1	2	3	4	5	B29.
f.	To what extent do worries about having an altered gene interfere with your everyday life?	1	2	3	4	5	B30.
g.	How often do you worry about your relatives developing breast or ovarian cancer?	1	2	3	4	5	B106.
h.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B107.
i.	How often do you worry about your relatives having an altered gene associated with risk for breast and ovarian cancer?	1	2	3	4	5	B108.
j.	To what extent do these worries interfere with your every day life?	1	2	3	4	5	B109.

Health, Mood, and Activities

1. In general, would you say your health is:

☐ Excellent
 ☐ Very Good
 ☐ Good
 ☐ Fair
 ☐ Poor

2. Compared to one year ago, how would you rate your health in general now?(**Check one**)

- ☐ Much better now than one year ago
- ☐ Somewhat better now than one year ago
- ☐ About the same as one year ago
- ☐ Somewhat worse now than one year ago
- ☐ Much worse than one year ago

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? *Please mark the appropriate box to indicate your response.*

		<i>YES, limited a lot.</i>	<i>YES, limited a little.</i>	<i>NO, not limited at all.</i>
a.	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.	1	2	3
b.	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.	1	2	3
c.	Lifting or carrying groceries.	1	2	3
d.	Climbing several flights of stairs.	1	2	3
e.	Climbing one flight of stairs.	1	2	3
f.	Bending, kneeling, or stooping.	1	2	3
g.	Walking more than a mile.	1	2	3
h.	Walking several blocks.	1	2	3
i.	Walking one block.	1	2	3
j.	Bathing or dressing yourself.	1	2	3

4. **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of your **physical** health?

4a. Cut down the amount of time you spent on work or other activities.

(1) ☐ Yes (5) ☐ No

4b. Accomplished less than you would like.

(1) ☐ Yes (5) ☐ No

4c. Were limited in the kind of work or other activities.

(1) ☐ Yes (5) ☐ No

4d. Had difficulty performing the work or other activities (for example, it took extra effort).

(1) ☐ Yes (5) ☐ No

5. **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of any **emotional** problems (such as feeling depressed or anxious)?

5a. Cut down the amount of time you spent on work or other activities. (1) ☐ Yes (5) ☐ No

5b. Accomplished less than you would like. (1) ☐ Yes (5) ☐ No

5c. Didn't do work or other activities as carefully as usual. (1) ☐ Yes (5) ☐ No

6. **During the past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

(1) ☐ Not at all (2) ☐ Slightly (3) ☐ Moderately (4) ☐ Quite a bit (5) ☐ Extremely

7. How much bodily pain have you had **during the past 4 weeks**?

(1) ☐ Not at all (2) ☐ Slightly (3) ☐ Moderately (4) ☐ Quite a bit (5) ☐ Extremely

8. **During the past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?

(1) ☐ Not at all (2) ☐ Slightly (3) ☐ Moderately (4) ☐ Quite a bit (5) ☐ Extremely

9. These questions are about how you feel and how things have been with you during the past **4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time **during the past 4 weeks**: *Please mark the appropriate box to indicate your response.*

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a.	Did you feel full of pep?	1	2	3	4	5	6
b.	Have you been a very nervous person?	1	2	3	4	5	6
c.	Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d.	Have you felt calm and peaceful?	1	2	3	4	5	6

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
e.	Did you have a lot of energy?	1	2	3	4	5	6
f.	Have you felt downhearted and blue?	1	2	3	4	5	6
g.	Have you been a happy person?	1	2	3	4	5	6
h.	Did you feel tired?	1	2	3	4	5	6

Mood Section

1. **During the past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?
☐ All of the time ☐ Most of the time ☐ A good bit of the time ☐ Some of the time ☐ A little of the time ☐ None of the time

2. **In the past 6 months**, have you had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I12.
(1) ☐ Yes (5) ☐ No (Skip to Question 3)
 - 2a. If there was such a two-week period in **the past 6 months**, did your work or relationships suffer? I12a.
(1) ☐ Yes (5) ☐ No
 - 2b. If there was such a two-week period in **the past 6 months**, did you get counseling or psychotherapy? I12b.
(1) ☐ Yes (5) ☐ No
 - 2c. If there was such a two-week period in **the past 6 months**, did you get medication for this condition? I12c.
(1) ☐ Yes (5) ☐ No

3. Have you **ever in your lifetime** had two weeks or more when nearly every day you felt sad, blue, or depressed or in which you lost all interest in things like work or hobbies or things you usually liked to do for fun? I14
(1) ☐ Yes (5) ☐ No (Skip to Question 4, next page)
 - 3a. If there was such a two-week period, did your work or relationships suffer? I14a.
(1) ☐ Yes (5) ☐ No
 - 3b. If there was such a two-week period, did you get counseling or psychotherapy? I14b.
(1) ☐ Yes (5) ☐ No
 - 3c. If there was such a two-week period, did you get medication for this condition? I14c.
(1) ☐ Yes (5) ☐ No

4. Are you **currently** receiving counseling, psychotherapy or medication for depression or emotional problems?

I13.

(1) ☐ Yes (5) ☐ No

Coping Section

1. Sometimes people can find unexpected benefits in difficulties. We are interested in the ways in which you might have made positive use of your knowing that you have an altered gene which increases the risk of breast cancer. For each of the statements below, indicate the degree to which your life has been affected positively by your finding you have an altered gene.

		<i>Not At All</i>	<i>A Very Small Degree</i>	<i>A Small Degree</i>	<i>A Moderate Degree</i>	<i>A Great Degree</i>	<i>A Very Great Degree</i>	
a.	My priorities about what is important in life.	1	2	3	4	5	6	L6a.
b.	I'm more likely to try to change things which need changing.	1	2	3	4	5	6	L6b.
c.	An appreciation for the value of my own life.	1	2	3	4	5	6	L6c.
d.	A feeling of self-reliance.	1	2	3	4	5	6	L6d.
e.	A better understanding of spiritual matters.	1	2	3	4	5	6	L6e.
f.	Knowing that I can count on people in times of troubles.	1	2	3	4	5	6	L6f.
g.	A sense of closeness with others.	1	2	3	4	5	6	L6g.
h.	Knowing I can handle difficulties.	1	2	3	4	5	6	L6h.
i.	A willingness to express my emotions.	1	2	3	4	5	6	L6i.
j.	Being able to accept the way things work out.	1	2	3	4	5	6	L6j.
k.	Appreciating each day.	1	2	3	4	5	6	L6k.
l.	Having compassion for others.	1	2	3	4	5	6	L6l.
m.	I'm able to do better things with my life.	1	2	3	4	5	6	L6m.
n.	New opportunities are available which wouldn't have been otherwise.	1	2	3	4	5	6	L6n.

2. This set of questions deals with ways you've been coping with the stress in your life that goes with knowing you have an altered gene associated with increased risk for breast cancer. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with it. Each item says something about a particular way of coping. We want to know *to what extent* you've been doing what the item says, how *much* or how *frequently*. Don't answer on the basis of whether it seems to be working, but just whether or not you're doing it. Use these response choices below and try not to let one answer influence another. Make your answers as true FOR YOU as you can.

		<i>I haven't been doing this at all</i>	<i>I've been doing this a little bit</i>	<i>I've been doing this some</i>	<i>I've been doing this a lot</i>	
a.	I've been turning to work or other activities to take my mind off things.	1	2	3	4	L7a.
b.	I've been concentrating my efforts on doing something about my situation.	1	2	3	4	L7b.
c.	I've been saying to myself "this isn't possible."	1	2	3	4	L7c.
d.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4	L7d.
e.	I've been getting emotional support from others.	1	2	3	4	L7e.
f.	I've been giving up trying to deal with it.	1	2	3	4	L7f.
g.	I've been taking action to try to make the situation better.	1	2	3	4	L7g.
h.	I've been refusing to believe that it is possible that I have an altered gene.	1	2	3	4	L7h.
i.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4	L7i.
j.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4	L7j.
k.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4	L7k.
l.	I've been trying to come up with a strategy about what to do.	1	2	3	4	L7l.
m.	I've been getting comfort and understanding from someone.	1	2	3	4	L7m.

		<i>I haven't been doing this at all</i>	<i>I've been doing this a little bit</i>	<i>I've been doing this some</i>	<i>I've been doing this a lot</i>	
n.	I've been giving up the attempt to cope.	1	2	3	4	L7n.
o.	I've been accepting the possibility that I might have an altered gene.	1	2	3	4	L7o.
p.	I've been expressing my negative feelings.	1	2	3	4	L7p.
q.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4	L7q.
r.	I've been learning to live with the possibility that I have an altered gene.	1	2	3	4	L7r.
s.	I've been thinking hard about what steps to take.	1	2	3	4	L7s.
t.	I've been praying or meditating.	1	2	3	4	L7t.
u.	I've been making fun of the situation.	1	2	3	4	L7u.

The following items are to be answered only by those women who are married or living with a partner.

☐ If not married or living with a partner skip to the Mood section, next page.

		<i>I haven't been doing this at all</i>	<i>I've been doing this a little bit</i>	<i>I've been doing this some</i>	<i>I've been doing this a lot</i>	
v.	I've been denying or hiding my anger around my spouse/partner.	1	2	3	4	Lv.
w.	I've been denying or hiding my worries around my spouse/partner.	1	2	3	4	Lw.
x.	I've been avoiding talking about my problems around my spouse/partner.	1	2	3	4	Lx.
y.	I've acted more positive around my spouse/partner than I feel.	1	2	3	4	Ly.

Symptoms of Strain Section

LISTED BELOW ARE SOME SYMPTOMS OF STRAIN THAT PEOPLE SOMETIMES HAVE. *Please Read Each One Carefully And Check The Answer Which Best Reflects How Much That Symptom Has Bothered You During the **Past Three Months**.*

		<u>Not at all</u>	<u>A little</u>	<u>Quite a bit</u>	<u>Extremely</u>	
1.	Suddenly scared for no reason	1	2	3	4	K1.
2.	Feeling fearful	1	2	3	4	K2.
3.	Faintness, dizziness, or weakness	1	2	3	4	K3.
4.	Nervousness or shakiness inside	1	2	3	4	K4.
5.	Heart pounding or racing	1	2	3	4	K5.
6.	Trembling	1	2	3	4	K6.
7.	Feeling tense or keyed up	1	2	3	4	K7.
8.	Headaches	1	2	3	4	K8.
9.	Spells of terror or panic	1	2	3	4	K9.
10.	Feeling restless, can't sit still	1	2	3	4	K10.
11.	Feeling low in energy--slowed down	1	2	3	4	K11.
12.	Blaming yourself for things	1	2	3	4	K12.
13.	Crying easily	1	2	3	4	K13.
14.	Loss of sexual interest or pleasure	1	2	3	4	K14.
15.	Poor appetite	1	2	3	4	K15.
16.	Difficulty falling asleep, staying asleep	1	2	3	4	K16.
17.	Feeling hopeless about the future	1	2	3	4	K17.
18.	Feeling blue	1	2	3	4	K18.
19.	Feeling lonely	1	2	3	4	K19.
20.	Feeling trapped or caught	1	2	3	4	K20.
21.	Worrying too much about things	1	2	3	4	K21.
22.	Feeling no interest in things	1	2	3	4	K22.
23.	Thoughts of ending your life	1	2	3	4	K23.
24.	Feeling everything is an effort	1	2	3	4	K24.
25.	Feelings of worthlessness	1	2	3	4	K25.

Relationships Section

1. Is there anyone in your life with whom you can share your most private feelings without holding back? (1) ☐ Yes (5) ☐ No C21.
2. Next, we are interested in any changes that getting the results of testing has had on your close relationships. How has your knowing your test results affected your relationship with the following relatives?

		Much less close	A Little Less Close	No Change	A Little More Close	Much More Close	No Living Relatives in this Category
a.	Spouse/Partner	1	2	3	4	5	-8
b.	Children	1	2	3	4	5	-8
c.	Parent(s)	1	2	3	4	5	-8
d.	Sister(s)	1	2	3	4	5	-8

3. Have any of your female relatives received their test results?
(1) ☐ Yes (5) ☐ No
4. Have any been told they **have** an altered gene for risk of breast cancer?
(1) ☐ Yes (5) ☐ No
5. Overall, has your relationship to them changed?

Much less close	A Little Less Close	No Change	A Little More Close	Much More Close
1	2	3	4	5

6. Have any been told they **do not have** an altered gene for risk of breast cancer?
(1) ☐ Yes (5) ☐ No
7. Overall, has your relationship to them changed?

Much less close	A Little Less Close	No Change	A Little More Close	Much More Close
1	2	3	4	5

Thank You Very Much For Your Participation!